the management of chronic illnesses, such as diabetes treatment, including good users' acceptance and an increase in their knowledge.² Knowledge acquisition is generally seen as a necessary condition for behavioral change. Applications with virtual humans offer a dynamic, interactive and easily accessible approach to enhance users' knowledge. We did not find published literature on the use of virtual humans to educate people with OA.

Objectives: To develop a web application to support education of caregivers and people with OA.

Methods: This is a proof of concept study, which builds on our previous experience with virtual assistant applications. For example, "Virtual Pharmacy"⁴ is intended to improve self-medication consultation skills between students/pharmacy professionals and community pharmacy clients, whilst "VASelfCare"³ aims to facilitate self-care of older people with type 2 diabetes (REF?).

The main principle underpinning the development of our application is the use of gamification embedded in a narrative with a double purpose of maintaining user engagement and enhancing the play experience. This option has in consideration that OA is more prevalent among the seniors and is supported by a study showing that embedding narratives in mobile games enhances the play experience of this age group.⁵

In our approach, the narrative comprises dialogues aiming to ease and stimulate the search for new knowledge, and to educate for disease management and health promotion.

Results: So far, we have developed NOA, a virtual assistant that interacts with users through speech (voice and subtitles) plus facial and body animations. NOA is a 2D cartoon female model that plays the role of a character who suffers from OA and provides information about her own experiences with the disease. At the end of each dialogue, a quiz tests users' knowledge. Awarding points and digital badges for correct answers, or showing the right answers when the user fails, are expected to motivate users to play and learn more. This application will be placed in the "Portuguese League Against Rheumatic Diseases" website to convey easy access.

Conclusion: Development of a virtual assistant web application to promote education on OA, resorting to a narrative approach and gamification principles, is ongoing. Future work includes testing the application with experts and patients.

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OP0287-PARE SETTING UP A EUROPEAN FEDERATION OF SJÖGREN'S SYNDROME PATIENT ASSOCIATIONS: HOW WE BUILT UP SJÖGREN EUROPE IN LESS THAN ONE YEAR

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Background: Despite its considerable prevalence among CTDs, SS has been devoted less research, interest, time and effort compared with other close conditions. Active and synergistic involvement of patients, clinicians and scientists in the definition of unmet needs and areas of future research is crucial.

Objectives: To set up a perennial European Federation of SS patient associations to address the lack of visibility and the unmet needs, foster patient training and involvement in research and articulate patient voices throughout Europe.

Methods: Sjögren Europe was conceived during the 2018 ISSS and the decision to materialize the Federation was launched during the EULAR 2018 congress, where several meetings with key entities representatives were organized to get advice on various aspects. A medical advisory board was also set up. By-laws, a logo and a website were created. The task force is composed of patients already involved in patient advocacy at a national and international level. The first step

was to set a mindset and to communicate on a regular basis to ensure a common spirit. We set priorities and down-to-earth objectives and focus on them. Although there is a leader for supervision and to take final decisions, the governance is mainly based on shared leadership sustained by trusted connections. Personal initiatives are encouraged, and failure is considered as a learning experience. We build a culture of compromise. As members experience debilitating fatigue, they achieve the tasks they can, whenever they have time and energy, and report them to the others: Sjögren Europe adapts to its members. We also welcome anyone sharing our mission principles and wanting to be involved in the project.

Results: On the 23rd of February 2019, Sjögren Europe was officially set up with more than 8 countries as founders. Being flexible not only allows patients with debilitating fatigue to work for the federation but also leads to lean and efficient procedures and tasks. An enthusiastic and supportive environment makes the commitment sustainable and meaningful. Face to face meetings, a good network and collaboration are imperative. The way we respond to mistakes is also crucial for motivation.

Conclusion: This project empowers the SS patient community, brings hope, injects a new energy in patient advocacy and breathes motivation for collaboration to researchers, scientists and clinicians. This presentation aims to share our story and the key learning points about the way we work and to spread the positive atmosphere.

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OP0288-PARE WHAT DO YOUNG PEOPLE THINK ABOUT CONTINUOUS DATA COLLECTION IN CLINICAL RESEARCH AND THE TYPES OF ELECTRONIC DEVICES?

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Background: The use of wearable devices are of increasing interest to enable continuous data collection during drug trials. This is particularly pertinent when involving young people who are "digital natives" and have grown up with such technologies.

Objectives: To ascertain opinions from young people regarding the design of wearable devices and the use of continuous data collection for a future clinical drug trial for juvenile idiopathic arthritis (JIA).

Methods: A three hour face-to-face patient involvement session was held in a young person friendly venue in central Manchester on the 8th December 2018. Young people with a rheumatic disease were invited to participate using event flyers provided in local rheumatology clinics. Members of a national youth advisory panel, Your Rheum, were also invited to attend. Data was collected in both large and small group discussions and included a ranking exercise involving the use of voting cards, emojis and pictures of electronic devices to aid conversations. In addition, an online survey was also developed and uploaded to <http://your-rheum.org> for young people to complete if they could not attend the event in person. Open questions (requesting free text answers) ranged from general thoughts and concerns about continuous data collection, device preferences and features, to examples of unattractive devices.

Results: Eight young people attended the event (M=5, F=3, 11-19 age range). All males were under 14 years of age. One young person completed the online survey (F=1). All participants regularly used some form of an electronic device and were generally willing to use a wearable device for continuous data collection, although consideration of school regulations (e.g. uniform policies) and potential bullying was necessary. Participants reported that they would choose a device based on its viability, look, comfort and functionality. For instance, the device would need to be discrete in terms of size, muted (no sounds or vibrations) and removable. The preference of device type differed by gender though a watch and patch were in the top three favourite devices for all. Key features included the

ability to switch devices on and off, send reminders, chat to other young people and to track their own data. Some caution was expressed about a device monitoring sleep (or other behaviours that parents may want to know about). It was important for participants to know where the data will be stored, who had access to it and what the information will be used for.

Conclusion: Young people have clear opinions as to what they like and don't like with respect to wearable data collection devices. As well as personal preferences, age specific considerations were highlighted by the young people. It is therefore imperative not only to involve young people as research participants but also to involve them at early stages of research including trial design to ensure acceptability of data collection methods including the design of any devices proposed.

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OP0289-PARE THE ROLE OF PATIENT ORGANISATIONS ON THE EDUCATION AND ESTABLISHMENT OF RHEUMATOLOGY NURSE

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Background: Rheumatology Nurse is a practitioner well educated or with a specialty on Rheumatology diseases who help people with RMD's to live as fully independently as possible. A Big Part of the rheumatology nurse's job is to help patients with rheumatic diseases to release their pain and manage their symptoms. In Europe, the use of rheumatology nurses for the treatment of rheumatism is becoming more and more popular. In my country, this is not the case. There is still a lot of work to be done to apply the rheumatology practitioner. That's why our organization is pushing the government to implement in the system Rheumatology Nurse.

Objectives: During discussions between our organization and the Ministry of Health for asking the use of rheumatology nurse in the rheumatology outpatient clinic, since we don't have a rheumatology inpatient clinic, Ministry refused to give the authorisation with the justification of not having any nurse specialist, educated or interested to be educated on the rheumatology fields. So this was a challenge for our organization: The "Nurse Education on Rheumatology".

Methods: The aim had various steps to achieve. The first step was to inform Government Nursing Services the significant of Rheumatology Nurse. The second step was to discuss with them the need for educated Nurses on rheumatology and their opinion. Third to persuade them to educate nurses on Rheumatology by organizing an Education Program. And the Last one but Very Important, part of the Education Program to be our organization not only as a presenter but to have an actual role as an associate with opinion, on the structure and themes of the program.

Results: The organisation had many meetings with the Government Nursing Services. The officers become very excited about the idea of having a New Education Program on such an interesting theme. After having a number of meetings about the development of the Program and after escaping the barriers, the program was done: Educational Program title "Patient Care with Rheumatic Diseases". Duration of the training: 3 months, 1 day per week, with 3 days of Clinical Exercise on outpatient Rheumatology Clinic and 1 Day on the Care Department-preparation and delivery of biological and biosimilar factors. Success in the Program requires Final Written Evaluation (60%) and Case study (Presentation). Patient Organization: 5 Lectures- Workshops. The education took place from October to December 2018. 27 Nurses have been educated. The program includes between a lot of Lectures, Patient Raise Awareness and Patient Perspective which were given by our Patient Organization. The lectures were given from Organizations' Psychologist staff and from Volunteers Patient Experts for

giving the patient perception for the treatment and for the self-management of their condition and Organization's Big Role regarding the disease awareness, treatment, and management. Organization conducted a survey among the participants and the results are very encouragingly to continue the tries to implement the Rheumatology Nurse in the outpatient and inpatient Rheumatology Clinics of the Country. At the question "after training will you be interested in working as a Rheumatology Nurse in a Rheumatology Clinic?" **The answer was YES for the 100% of the participants.**

Conclusion: The importance of nurses' involvement in the treatment of rheumatic diseases is enormous. This has been demonstrated in Europe. Our Organization shows the significant role of nurses for achieve the maximum results on the patient treatment. Also the organization has been able to prove the importance of the contribution of patients to better treatment of the disease. It has also demonstrated to the state the need for a Rheumatology Nurse and refutes their excuses.

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FRIDAY, 14 JUNE 2019

Rheumatoid arthritis – etiology, pathogenesis and animal models

OP0290 HOTAIR IS INVOLVED IN JOINT PATTERNING BY REGULATING FGFR2, BMP2 AND WNT PATHWAYS

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Background: Different forms of chronic arthritis such as rheumatoid arthritis (RA) or spondyloarthritis show a typical pattern of joint involvement. However, mechanisms involved in this patterning remain unknown. Synovial fibroblasts (SF) isolated from different joint regions, differ in their epigenetic landscape, their gene expression and their function. The long non-coding RNA HOTAIR, which is an important regulator of the epigenetic landscape, was found to be exclusively expressed in joints of the lower extremity.

Objectives: We aim to clarify the role of HOTAIR in SF.

Methods: HOTAIR was silenced in knee SF isolated from patients with osteoarthritis (OA) by HOTAIR GapmeR using Lipofectamine, and changes in gene expression were measured by next generation RNA sequencing (Illumina Nova-Seq 6000) after 48h (n=3). Pathway analysis was performed using STRING protein network, and regulated genes were confirmed by real-time PCR in SF silenced for HOTAIR from OA and RA-patients (n=8) and compared with control SF transfected with Antisense LNA GapmeR negative control. The time course of targeted genes was studied with and without cycloheximide (10µg/ml 6h and 24h) (n=2). To assess the effect of HOTAIR silencing on the canonical Wnt pathway, we employed the TOP/FOP reporter system using the dual-luciferase kit (n=3). Regulation of HOTAIR and targeted genes expression was studied after stimulation with TNF-α (n=17), IL1, LPS, TLR2, TLR4 and poly I:C (n=5). The expression of HOTAIR and TNF-α were measured in synovial tissue from RA-patients (n=7) by qPCR.

Results: STRING analysis identified among others three significantly enriched pathways, namely FGF, BMP and Wnt, including 19 genes differentially expressed between SF silenced for HOTAIR and controls according to p-value (<0.05) and log ratio (>2.5 or <-2.5). Real-time PCR confirmed 6 genes: FGFR2 (5 ± 0.1-fold downregulated; p<0.01), FGF7 (1.9± 0.4-fold downregulated; p=0.02), BMP2 (1.7± 0.5-fold upregulated; p<0.01), LGR5 (3.4±0.3-fold downregulated; p=0.02), CTNNB1 (beta-catenin) (1.5±0.5-fold upregulated; p<0.01) and GSK3β (1.8± 0.2-fold downregulated; p=0.03). There was a trend for LRP6 (p=0.06). HOTAIR expression and FGFR2 and FGF7 expression were correlated (r= 0.67 and 0.55; p<0.01) as well as HOTAIR and BMP2 (r=-0.45; p<0.05). Time course of gene expression peaked after 30-48 hours. Adjunction of cycloheximide, blocking translation, did not change gene expression of BMP2 and CTNNB1 in SF silenced for HOTAIR, suggesting a direct effect of HOTAIR on these genes. FGFR2, FGF7, LGR5, LRP6 and GSK3β expression were normalized with cycloheximide indicating the need of a protein to mediate HOTAIR effect on FGF pathway and on Wnt pathway. TopFlash assay confirmed the role of HOTAIR in regulation of Wnt pathway by 1.7± 0.2-fold decrease in Wnt activation after HOTAIR silencing (p=0.02). Stimulation by TNF-α led to a 2.1± 0.3 decrease in HOTAIR expression (p<0.0001). Following TNF-α stimulation, FGFR2 and LGR5 expression decreased (p=0.0001 and 0.0004, respectively), whereas there was an increase in BMP2 expression (p<0.0001), consistent with the effect of silencing HOTAIR on these genes. There was a decrease in HOTAIR expression following LPS (p=0.006), and poly I:C (p=0.003). HOTAIR and TNF-α were inversely correlated in the synovium of RA patients (r=-0.79; p<0.05).

Conclusion: Our study highlights three main pathways regulated by HOTAIR and involved in joint patterning: FGFR2/FGF7, BMP2 and LRP6/LGR5/GSK3β/