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.

REFERENCES:

- [1] Chou, L., et al. (2018). Patients' perceived needs of osteoarthritis health information: A systematic scoping review. *PloS one*, 13(4), e0195489
- [2] Finkelstein, J., & Bedra, M. (2014). Avatar-based Interactive Diabetes Education in Older Adults. *Journal of the American Geriatrics Society*, 62(S1), S64
- [3] <http://vaselfcare.rd.ciencias.ulisboa.pt/>
- [4] Cláudio, A. P., et al. (2016). Virtual Humans Playing the Role of Patients in Self-medication Consultations: Perspectives of Undergraduate Pharmacy Students. *GRAPP 2016*, pp 296-303
- [5] Yee, S. L. C. Y., et al. (2010). Investigating narrative in mobile games for seniors. *CHI 2010*, pp 669-672

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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.

REFERENCE:

- [1] Romão V. C., Talarico R., Scirè C. A., et al. *Sjögren's syndrome: state of the art on clinical practice guidelines* RMD Open 2018; 4:e000789. doi: 10.1136/rmdopen-2018-000789

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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