

model developed for national decision-making. We replicated an existing PLS model of this type to evaluate the advantages and disadvantages of different software. **Methods:** The model was originally created for a NICE clinical guideline on hyperphosphataemia in chronic kidney disease (CG157). It was built in visual basic for applications (VBA). PLS was chosen because it allowed the model to translate continuous biochemical measures from trials into effects on patient-relevant outcomes. We replicated the VBA model in Simul8[®], a dedicated simulation environment, to explore differences in build-time, results, run-time and usability. **Results:** The Simul8[®] implementation was slower than the original VBA model when simulating 8 cohorts of 10,000 patients (approximately 12 minutes versus 7.5 minutes). The model structure required the use of multiple patient-level variables ('labels') in Simul8[®], which are known to affect run-time. When event-logs were recorded for debugging, both VBA and Simul8[®] took considerably longer and Simul8[®] crashed frequently. Model validation was challenging due to the stochastic nature of PLS. When potentially non-trivial differences emerged between implementations, it was difficult to determine whether these were due to technical errors, Monte-Carlo error, or bias from different pseudo-random number generators, an area in which VBA is known to perform poorly. Object-oriented VBA was difficult for new users to grasp and coding errors were difficult to identify. The Simul8[®] interface allowed for patients' routes through the model to be easily visualised and tracked; however, some simple operations (e.g. lookups across categories) required convoluted coding. **Conclusions:** It is not clear that dedicated simulation software provides meaningful benefits over a generic scripting language for PLS. We are extending this project to encompass further replications in R and discretely integrated condition event simulation (DICE).

Urinary/Kidney Disorders - Patient-Centered Research

PUK31 ESTIMATING THE IMPACT OF TREATING CHRONIC KIDNEY DISEASE-ASSOCIATED PRURITUS ON QUALITY OF LIFE IN THE ABSENCE OF DIRECT UTILITY MEASURES

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Objectives: Chronic kidney disease-associated pruritus (CKD-aP) is a debilitating condition, significantly impacting quality of life (QoL) of patients on hemodialysis (HD). In the absence of utility data directly measuring this impact, we used available patient-reported outcomes (PRO) instruments to simulate EQ-5D-5L health profiles. **Methods:** We assessed different approaches to map individual questions and their rating from Skindex-10 (Sk-10) and 5D-Itch Scale (5-D) to the five dimensions of the EQ-5D and applied this mapping to data from a phase-2-study in 174 CKD-aP patients treated with difelikefalin (DFK) 0.5, 1.0, and 1.5 mcg/kg or placebo that collected itch intensity, Sk-10 and 5-D, but no EQ-5D data. EQ-5D-5L tariffs from United Kingdom (UK) and United States (US) were used to calculate utilities. **Results:** Using the UK tariff, patients with moderate to severe CKD-aP showed substantial utility impairment (baseline score between 0.15 and 0.35 depending on mapping used). The US tariff resulted in a higher baseline of 0.39 – 0.53, reflecting different valuations in diverse populations. DFK-treated Patients significantly improved their utility to 0.52 – 0.63 (UK tariff) or 0.64 to 0.71 (US tariff) respectively (all $p < 0.05$). Main driver of the improvements were lower severity of reported problems in the EQ-5D Self-Care and Pain / Discomfort dimensions. Patients receiving placebo registered a lower improvement to 0.35 – 0.5 (UK) or 0.54 – 0.64 (US). These results are consistent with the statistically significant improvement over time and relative to placebo measured with both Sk-10 and 5-D. **Conclusions:** While absolute values vary between countries, data from this study demonstrates that HD patients with moderate to severe CKD-aP have lower QoL than HD patients in general. Treatment that improves itch-related QoL (as demonstrated by improvements on Sk-10 and 5-D PROs) results in higher utility values, which are close to those previously measured in HD patients in other studies.

PUK32 PATIENT INSIGHTS FOR IMMUNOGLOBULIN A NEPHROPATHY (IGAN) USING SOCIAL MEDIA LISTENING

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Objectives: There is a lack of published evidence on the humanistic burden of IgAN; a rare renal condition. The objective of this study was to understand the patient journey, quality of life (QoL) and unmet needs from the patients' perspective. **Methods:** Social media data from February 2017–September 2018 were captured based on a predefined search strategy using MeSH terms, through social media data aggregator. IgAN specific social media discussions in English language originating from the US and the UK, on open channels such as twitter, forums, blogs and newswires were analyzed, post anonymization. **Results:** A total of 1,336 relevant posts were analyzed. Patients/caregivers conversations were mainly focused on seeking or sharing advice, information and experiences on IgAN. The presence of "cola coloured urine/blood in the urine" or "foamy urine" were the major reasons leading to physician visits. Diagnosis usually happened at 21–30 years of age, mainly through biopsy. The absence of detailed information on the disease and counseling caused emotional stress on patients/caregivers. Many of the posts mentioned initial treatment with anti-hypertensives followed by steroids and/or immunosuppressants. Approximately one-third of patients discussed progressing to end-stage renal

disease within 7–12 years, needing dialysis and some patients also mentioned requiring transplant, adding to the disease burden. Symptoms like fatigue and pain restricted physical activity, emotions like fear of disease progression, anxiety, and depression and dialysis requirement affected the QoL. **Conclusions:** This study provides insights into how patients perceive and live with their disease. The symptoms of fatigue and pain, minimally mentioned previously in the literature, contributed to the reduction in the QoL, which needs further exploration in future studies. Furthermore, these insights can help better understand patients' perspective which can be taken into account during future drug development.

PUK33 PATIENT INSIGHTS FOR COMPLEMENT 3 GLOMERULOPATHY (C3G) USING SOCIAL MEDIA LISTENING

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Objectives: Published evidence on the humanistic burden of C3G, an ultra-rare renal condition, are scarce. This social media study was conducted to understand the patient journey, quality of life (QoL) and unmet needs from the patients' perspective. **Methods:** Social media data from September 2015–September 2018 were captured based on a predefined search strategy using MeSH terms, through social media data aggregator. C3G specific social media posts in English language from the US and the UK, on open channels such as twitter, forums, blogs and newswires were analyzed, post anonymization. **Results:** A total of 791 relevant posts were analyzed. The focus of the discussions, mainly driven by patients and caregivers, were on seeking or giving advice in regards to diagnosis and treatments, obtaining information on C3G and looking for support groups. The major reasons that led patients to physician visits were edema, fatigue, presence of blood in the urine and hypertension. Diagnosis was reported mainly in patients aged ≤ 20 years, through biopsy. Nearly 50% of mentions involved initial treatments with anti-hypertensives followed by steroids and/or immunosuppressants. Dialysis and transplant were mentioned as treatment options, adding significant emotional and physical burden. In addition, symptoms like feeling very weak and tired, swellings and always getting sick affected the patients' day to day activities. C3G patients and their caregivers felt uncertainty about transplant success and anxiety around their future. The absence of proper information in the public domain and counseling support emerged as unmet needs which caused more emotional stress among patients and caregivers. **Conclusions:** The symptoms and emotions associated with the disease reduced the QoL of both patients and caregivers. Furthermore, these patients' insights shed light on the disease burden from a patients' perspective and can be taken into account for future drug development programs.

PUK35 THE BURDEN OF INCONTINENCE IN A REAL-WORLD DATA ENVIRONMENT - INSIGHTS FROM A DIGITAL PREVENTION COMPANION

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Objectives: Urinary Incontinence (UI) can have a devastating effect on women's quality of life in many spheres. During pregnancy and after delivery, the strength of the pelvic floor may decrease resulting in a high rate of UI. Treatment by means of pelvic floor training is the treatment modality of first choice. Nowadays this can be supported by digital apps. Those have the advantage of giving insights into real world data on UI. The aim of the present study was to analyze the impact of UI on Quality of Life (QoL). **Methods:** We analyzed the data of pelvina® - a digital health companion pelvic floor course. This course examines incontinence symptoms through "The Questionnaire for Urinary Incontinence Diagnosis" (QUID) and QoL through SF-6D. Subsequently, the incidence and degree of incontinence in a real world environment was analyzed and the influence of different demographic factors determined. In addition, the impact of UI on the QoL was analyzed in more detail. **Results:** 293 patients with a median age of 36 years and a median of 2 deliveries could be included in this study. Patients were slightly to moderate affected by UI with a QUID of 6 (2 – 11, max: 24). Age and parity were independently associated with the incidence of UI with an aOR of 1.06 (95% CI 1.01 – 1.12) and aOR of 1.86 (95% CI 1.12 – 3.08) respectively. The severity of incontinence symptoms showed a strong correlation to the impairment in the QoL ($r = 0.489$, $P < 0.001$). **Conclusions:** For the first time, the use of real-world data, as generated by apps such as pelvina®, gives insight into the reality of patients' lives outside classical clinical studies. We find a strong association between parity and UI and the great influence UI has on QoL in daily life.

Urinary/Kidney Disorders - Real World Data & Information Systems

PUK36 DIRECT HEALTHCARE COSTS OF CHRONIC KIDNEY DISEASE MANAGEMENT IN ITALY: HOW MUCH SAVING CAN BE ACHIEVED WITH LARGER BIOSIMILAR UPTAKE?

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