

## ALC manuscripts 2021

1. **Lloyd A, Aggio D**, Slocomb TL, Lee J, Beggs AH, Bilder D. Estimation of the Quality-of-Life Impact of X-Linked Myotubular Myopathy. *Journal of Neuromuscular Diseases*. 2021 Jan. DOI: <https://doi.org/10.3233/JND-210686>
2. **Williams K, Skrobanski H**, Werner C, O'Neill S, Buesch K, **Acaster S**. Symptoms and impact of aromatic l-amino acid decarboxylase (AADC) deficiency: A qualitative study and the development of a patient-centred conceptual model. *Current Medical Research and Opinion*. 2021 May. DOI: <https://doi.org/10.1080/03007995.2021.1932449>
3. **Skrobanski H, Williams K**, Werner C, O'Neill S, Buesch K, **Acaster S**. The impact of caring for an individual with aromatic l-amino acid decarboxylase (AADC) deficiency: a qualitative study and the development of a conceptual model. *Current Medical Research and Opinion*. 2021 Oct. DOI: <https://doi.org/10.1080/03007995.2021.1955668>
4. **Williams K, Aggio D**, Chen P, Anokhina K, **Lloyd AJ**, Wang Y. Utility Values Associated with Atypical Hemolytic Uremic Syndrome-Related Attributes: A Discrete Choice Experiment in Five Countries. *PharmacoEconomics*. 2021 Aug. DOI: <https://doi.org/10.1007/s40273-021-01059-w>
5. **Lo SH**, Marshall J, **Skrobanski H, Lloyd A**. Patient and Caregiver Health State Utilities in Tuberous Sclerosis Complex. *PharmacoEconomics-Open*. 2021 Sep. DOI: <https://doi.org/10.1007/s41669-021-00296-1>
6. **Lo SH, Lloyd A**, Elkhalfa S, Sisic Z, van Nooten FE. Time Trade-Off Utilities for Hereditary Angioedema Health and Caregiver States. *PharmacoEconomics-Open*. 2021 Sep. DOI: <https://doi.org/10.1007/s41669-021-00302-6>
7. **Gallop K, Lloyd AJ**, Olt J, Marshall J. Impact of developmental and epileptic encephalopathies on caregivers: A literature review. *Epilepsy & Behavior*. 2021 Nov. DOI: <https://doi.org/10.1016/j.yebeh.2021.108324>
8. **Williams K**, Davidson I, Rance M, Buesch K, **Acaster S**. A qualitative study on the impact of caring for an ambulatory individual with nonsense mutation Duchenne muscular dystrophy. *Journal of Patient-Reported Outcomes*. 2021 Dec. DOI: <https://doi.org/10.1186/s41687-021-00344-8>
9. **Williams K**, Davidson I, Rance M, Boehnke A, Buesch K, **Acaster S**. Symptoms and impacts of ambulatory nonsense mutation Duchenne muscular dystrophy: a qualitative study and the development of a patient-centred conceptual model. *Journal of Patient-Reported Outcomes*. 2021 Dec. DOI: <https://doi.org/10.1186/s41687-021-00341-x>
10. **Lo SH**, Gorni K, Sutherland CS, Martí Y, **Lloyd A**, Paracha N. Preferences and utilities for treatment attributes in type 2 and non-ambulatory type 3 spinal muscular atrophy in the United Kingdom. *PharmacoEconomics*. 2021 Oct. DOI: <https://doi.org/10.1007/s40273-021-01092-9>
11. **Lo SH, Lloyd A**, Marshall J, Vyas K. Patient and Caregiver Health State Utilities in Lennox-Gastaut Syndrome and Dravet Syndrome. *Clinical therapeutics*. 2021 Nov. DOI: <https://doi.org/10.1016/j.clinthera.2021.09.017>

12. **Lo SH**, Lawrence C, Martí Y, Café A, **Lloyd AJ**. Patient and caregiver treatment preferences in type 2 and non-ambulatory type 3 spinal muscular atrophy: a discrete choice experiment survey in five European countries. *PharmacoEconomics*. 2021 Dec. DOI: <https://doi.org/10.1007/s40273-021-01118-2>
13. **Lo SH**, Sharma R, Costentin CE, **Aggio D**, Shergill S, Colaone F, Brennan VK, Straccia VA, Agirrezabal I, **Lloyd AJ**. Patient preferences for advanced hepatocellular carcinoma treatment: a multicountry stated preference study. *Future Oncology*. 2021 Jul. DOI: <https://doi.org/10.2217/fon-2021-0697>
14. Gerbasi ME, Kosinski M, Meltzer-Brody S, **Acaster S**, Fridman M, Huang MY, Bonthapally V, Hodgkins P, Kanés SJ, Eldar-Lissai A. Achieving clinical response in postpartum depression leads to improvement in health-related quality of life. *Current Medical Research and Opinion*. 2021 Mar. DOI: <https://doi.org/10.1080/03007995.2021.1902295>
15. Biolcatti G, Hanneken S, Minder EI, Neumann NJ, Wilson JH, Wolgen PJ, Wright DJ, **Lloyd AJ**. Validation of a novel patient reported tool to assess the impact of treatment in erythropoietic protoporphyria: the EPP-QoL. *Journal of Patient-Reported Outcomes*. 2021 Dec. DOI: <https://doi.org/10.1186/s41687-021-00345-7>
16. Crossnohere NL, Fischer R, **Lloyd A**, Prosser LA, Bridges JF. Assessing the Appropriateness of the EQ-5D for Duchenne Muscular Dystrophy: A Patient-Centered Study. *Medical Decision Making*. 2021 Feb. DOI: <https://doi.org/10.1177/0272989X20978390>
17. Nafees B, **Lloyd A**, Dewilde S. Estimating health state utilities in hemophagocytic lymphohistiocytosis. *Journal of Patient-Reported Outcomes*. 2021 Dec. DOI: <https://doi.org/10.1186/s41687-020-00276-9>.
18. Canonica GW, Klimek L, **Acaster S**, Dollner R, Kaulsay R, **Lo SH**, Price DB, Scadding GK, Valovirta E, Ziegelmayer P. Burden of allergic rhinitis and impact of MP-AzeFlu from the patient perspective: pan European patient survey. *Current Medical Research and Opinion*. 2021 Apr. DOI: <https://doi.org/10.1080/03007995.2021.1911973>
19. Blome C, Carlton J, Heesen C, Janssen MF, **Lloyd A**, Otten M, Brazier J. How to measure fluctuating impairments in people with MS: development of an ambulatory assessment version of the EQ-5D-5L in an exploratory study. *Quality of Life Research*. 2021 Mar. DOI: <https://doi.org/10.1007/s11136-021-02802-8>
20. Zoratti MJ, Pickard AS, Stalmeier PF, Ollendorf D, **Lloyd A**, Chan KK, Husereau D, Brazier JE, Krahn M, Levine M, Thabane L. Evaluating the conduct and application of health utility studies: a review of critical appraisal tools and reporting checklists. *The European Journal of Health Economics*. 2021 Apr. DOI: <https://doi.org/10.1007/s10198-021-01286-0>
21. Matza LS, Stewart KD, **Lloyd AJ**, Rowen D, Brazier JE. Vignette-Based Utilities: Usefulness, Limitations, and Methodological Recommendations. *Value in Health*. 2021 Jun. DOI: <https://doi.org/10.1016/j.jval.2020.12.017>
22. Verstraete J, **Lloyd AJ**, Jelsma J. Performance of the Toddler and Infant (TANDI) Health-Related Quality of Life Instrument in 3–4-Year-Old Children. *Children*. 2021 Oct. DOI: <https://doi.org/10.3390/children8100920>