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**Title:** A slower life in a smaller world. Patients' perspective on living with pulmonary arterial hypertension

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**Body:** Background: The pulmonary arterial hypertension (PAH) patient management pathway is often defined from the clinician or commissioner perspective. We wanted to gain an in-depth understanding of the patient self reported experience living with PAH. Objectives: Working to understand how a diagnosis of PAH impacts a patient's life. Exploring the journey through first symptoms to specialist care and the 'life changes' needed. Methods: Over 1000 General Practitioners were approached to put forward patients with PAH to participate in semi-structured, in depth qualitative interviews designed to determine the key themes emerging from the individual experiences of PAH. Interviews were audio-recorded for subsequent analysis using interpretive phenomenological analysis methodology. Results: A total of 8 patient interviews were analysed who had the following underlying aetiologies: IPAH (n=3) and ACHD (n=5), aged between 30 – 70 years and treated with different targeted PAH therapies. Patients interviewed were being managed at 4 different PAH Specialist Centres in the UK. Areas where patients' needs were perceived not to be met by healthcare delivery included: 1) patient information materials did not cover PAH impact on co-morbidities, 2) dealing with a crisis on their own, 3) effective counseling when treatment fails, 4) securing disability allowance, 5) being able to live a normal life, 6) minimising the impact on their family. Conclusions: Specific areas have been highlighted where healthcare delivery does not meet patients' needs. Living with a rare disease has its own unique challenges requiring careful consideration with potential to further improve the patient experience.