Introduction and Aims: Adult polycystic kidney disease (APKD) is a common cause of chronic kidney disease and progression to ESKD: in West London 5.4% of patients starting renal replacement therapy have APKD. Currently no specific treatments are licensed for patients with APKD, however recent controlled trials (of tolvaptan) have demonstrated possible benefits in slowing progression of renal failure in treated patients, suggesting possible use clinically in the near future. We aimed to determine the real-world clinical work load and health economic considerations should a drug become licensed for routine use in patients with APKD requiring more frequent follow-up (5 visits in 1st year) and repeated imaging (MRI volumes) than currently performed in routine clinical practice.

Methods: we identified all patients currently diagnosed clinically with APKD under follow-up in our renal centre from electronic records, demographic details, current renal function from routinely obtained serum creatinine and eGFR, historic measures of sCreatinine, details of previous imaging and current outpatient attendances. Analysis was undertaken for prevalent patients and will underestimate work given ongoing accrual of incident patients.

Results: Our centre serves a population of approx 2.4 million; we identified 301 living patients with APKD and CKD (not on dialysis) under active follow-up, a further 122 receiving RRT (giving total population prevalence approx 186 per million). Mean age was 50.6 yrs (sd 15: 18-85), mean eCreat 138 mcmol/L (37-775), mean eGFR 45 ml/min (5->90); 152 patients (53%) had CKD stage 1-2, 26% CKD stage 3, and 21% CKD stage 4 or 5 (not on dialysis). 19% of patients with CKD stage 1/2 and 67% of patients with CKD stage 3 lost significant renal function over 3 years. Only 11% of patients had a documented MRI scan, and 54% an ultrasound in the last 5 years, and 24% repeated imaging of any modality. Current routine management for patients with CKD stage 2 & 3 utilised 269 individual outpatient visits per year average duration 15 mins (total 67 hrs). If all these patients started a new therapy requiring one visit at 6 weeks and then 3-monthly this would require 289 hrs of outpatient time annually: including those with stage 4 CKD would require a further 61 hrs outpatient time. 440 additional MRI scans would be needed over 3 years if kidney volumes measures were being used. The costs of this extra care have been calculated for the NHS using a detailed analysis based on the results of the TEMPO trial data. Our single centre would require at least one full day of new outpatient clinics every week to meet this workload. This could be significantly modified depending on the specific selection criteria for any new therapy.

Conclusions: Institution of a new therapy for patients with APKD would have significant resource implications in addition to the drug cost itself which should be carefully considered and should form part of any detailed health economic analysis. This will require both physical and financial support within renal and imaging centres: our unit might need at least one new full day of clinical outpatient services every week.