

# CENTRE-LEVEL VARIATION IN TOLVAPTAN PRESCRIBING FOR ADPKD IN THE UK

M Gittus<sup>1</sup>, L Downward<sup>2</sup>, D Pitcher<sup>2</sup> & J Fotheringham<sup>1</sup>

<sup>1</sup>University of Sheffield School of Health Related Research (SchARR), <sup>2</sup>The National Registry of Rare Kidney Diseases (RaDaR)

## BACKGROUND

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the leading inheritable cause of adult End Stage Renal Disease.

Tolvaptan was approved by the National Institute for Health and Care Excellence (NICE) and Scottish Medicines Consortium (SMC) in 2015. It represents the only disease-modifying technology that has been shown to slow the growth of renal cysts and decline in renal function. The UK Kidney Association provided further advice in the form of a commentary on the NICE guidance. Despite this guidance, NHS Digital data and anecdotal experience suggest there is variation in usage across UK renal centres.

## AIM

To examine the current prescribing practices and prescriber adherence to recommendations for tolvaptan in the management of ADPKD at a renal centre level.

## METHODS

A retrospective cohort study of people with ADPKD within the UK registered to the National Registry of Rare Kidney Diseases (RaDaR).

Patients who were initiated on tolvaptan were assessed for eligibility for initiation according to the UKKA commentary on NICE guidance. The potential groupings are demonstrated in the Venn diagram.

Indications to initiate tolvaptan:

- 30-90 ml/min/1.73m<sup>2</sup> (CKD 2-3)
- 5-year eGFR slope  $\geq 2.5$  ml/min/1.73m<sup>2</sup> or 1-year eGFR slope  $\geq 5$  ml/min/1.73m<sup>2</sup>

Patients were grouped by UK renal centre. Variation was assessed using funnel plots adjusted for overdispersion (excess variation) where appropriate.



## Summary

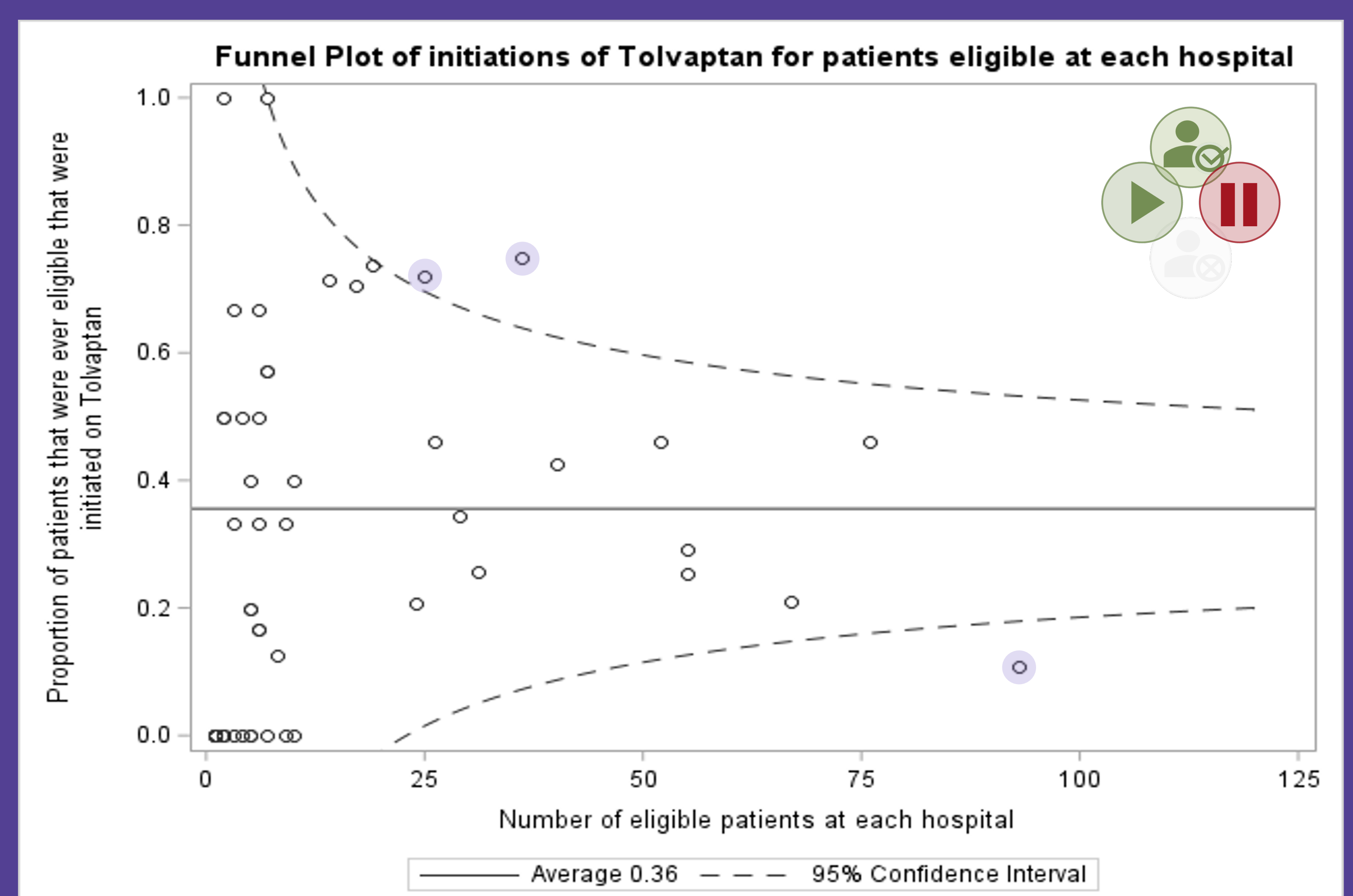
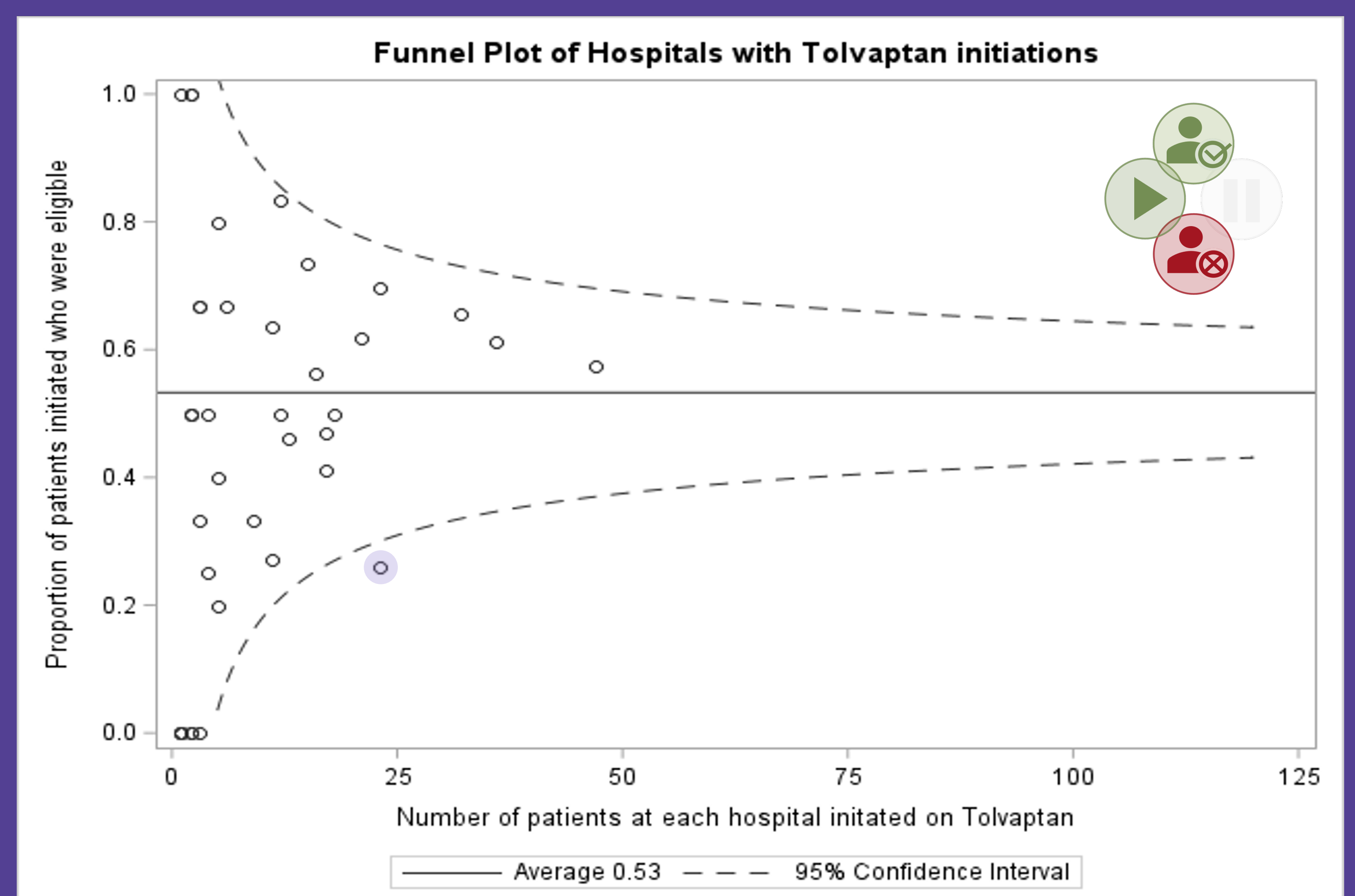
- 396 patients were initiated on tolvaptan in study period
- Mean eGFR 49 at initiation
- Mean 1-year eGFR slope 4.9
- Mean 5-year eGFR slope 2.8

## Initiation/eligibility

- 246 of 396 patients initiated on tolvaptan were eligible (53%)
  - 45% met the 1-year eGFR slope criteria
  - 33% met the 5-year eGFR slope criteria
  - 5% met both criteria
- 297 of 824 eligible patients were initiated (36%)

## Centre variation

- Mean 2.5 of eligible patients initiated per centre (0-27)
- 45 centres had no eligible patients and 37 had fewer than 12 patients



## DISCUSSION

Adherence rates for medications used in common diseases range from 30-70%. This data demonstrated similar adherence rates for tolvaptan prescribing according to the guidance in the UKKA guidance. To achieve access to this sole disease-modifying medication, healthcare professionals may start tolvaptan inappropriately when ineligible according to UKKA guidance.

The high number of eligible patients not initiated on tolvaptan could represent unequal access to this sole disease-modifying therapy.

Further research is required to explain the variation in tolvaptan prescribing between the different UK-based renal departments.

[m.gittus@sheffield.ac.uk](mailto:m.gittus@sheffield.ac.uk)



**Acknowledgements:**  
We would like to thank the statistics team at RaDaR for their support