

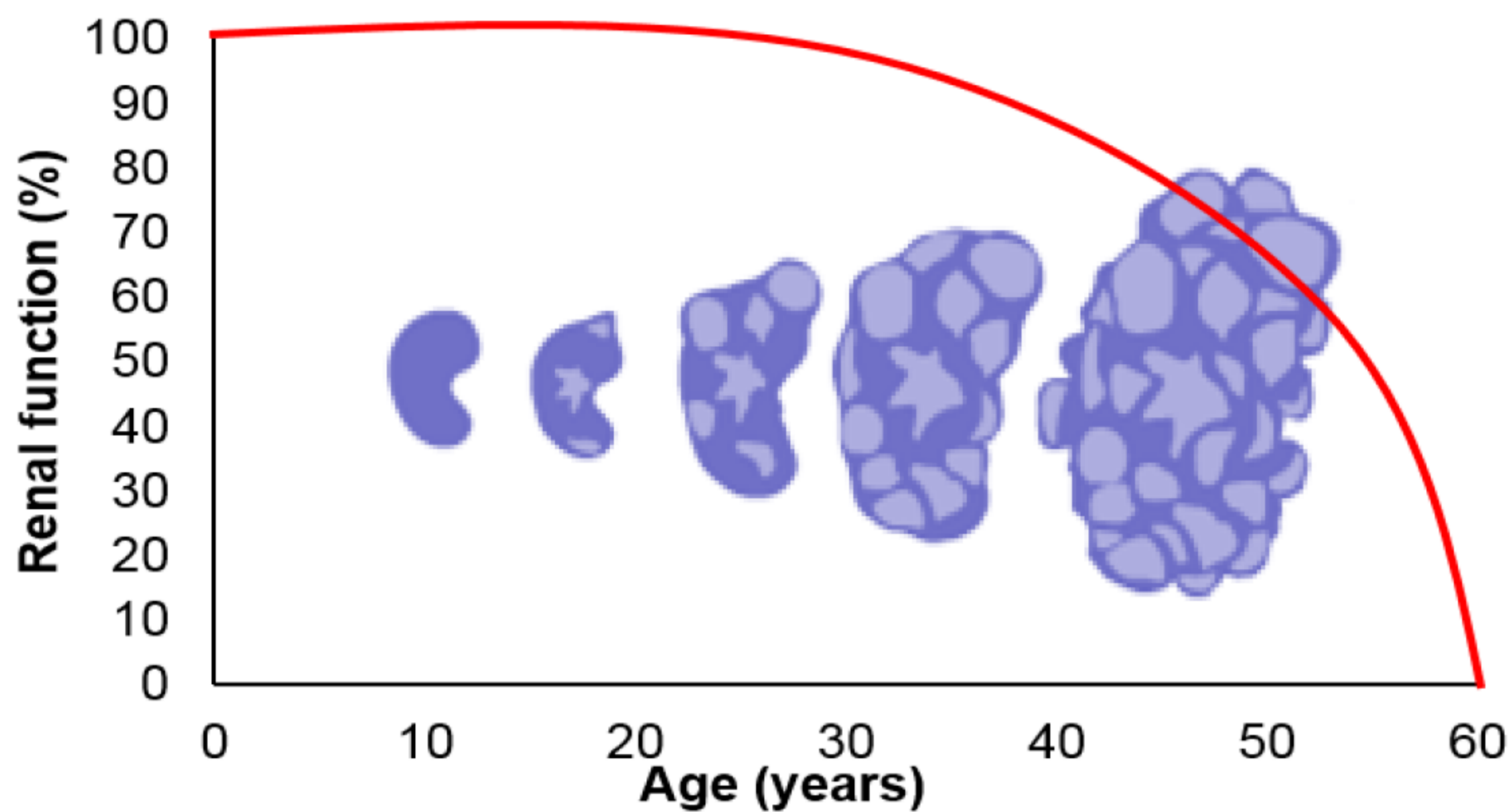
Increased Psychosocial Burden and Adverse Quality of Life in Autosomal Dominant Polycystic Kidney Disease

Roslyn J Simms^{1,2}, Kah Mean Thong^{1,2,3}, Gabriel C Dworschak^{1,2}, Albert CM Ong^{1,2}

¹Kidney Genetics Group, Academic Unit of Nephrology, University of Sheffield, UK; ²Sheffield Kidney Institute, Northern General Hospital, Sheffield, UK; ³Hospital Raja Permaisuri Bainun, Ipoh, Malaysia. Correspondence: r.simms@sheffield.ac.uk

Background

- Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the commonest genetic cause of end-stage renal failure.
- It is characterised by the gradual progressive development and growth of cysts throughout the kidneys.



- Patients with ADPKD suffer a well described physical burden but the psychosocial impact is poorly understood.

Objective

- To assess the quality of life (QOL), mood, perceived social support and psychosocial risk in patients registered at Sheffield Kidney Institute (SKI).

Methods

- 349 patients with ADPKD, not on renal replacement therapy (RRT), received a postal questionnaire which incorporated 3 validated forms:
 - KDQOL SF1.3 to assess QOL;
 - PHQ9 to screen for depression;
 - MSPSS to evaluate perceived social support.
- An additional novel instrument (Sheffield ADPKD PSRI) to study the psychosocial impact of coping with a diagnosis of ADPKD was included.
- Patients were grouped by kidney function (eGFR >60ml/min, 30-60ml/min and <30ml/min) or kidney size (mean kidney length (KL) (<17cm or ≥17cm) on ultrasound.
- Statistical analyses were performed using SPSS.

Results

- This table shows the baseline characteristics of participants.
- 96% were white. Patients who were retired were significantly more likely to have an eGFR<30ml/min.

Variable	eGFR<30 (n=36)	eGFR 30-60 (n=38)	eGFR>60 (n=65)	p
Age	66.3 ± 13.1	56.2 ± 10.6	44.7 ± 14.1	<0.001
BMI (n=118)	28.3±5.4	27.7±5.3	26.9±4.8	0.466
Gender: Female	19 (52.8)	20 (52.6)	42 (64.6)	0.364
Married (n=137): Yes	23 (65.7)	27 (73)	40 (61.5)	0.505
Education (n=137): Voc./Higher degree	16 (45.7)	18 (48.6)	43 (67.2)	0.062
Smoker Current/Ex	19 (52.8)	15 (39.5)	28 (43.1)	0.487
FH of ADPKD (n=137): Yes	25 (69.4)	28 (73.7)	50 (79.4)	0.616*
Comorbidity: Yes	34 (94.4)	35 (92.1)	46 (70.8)	0.002
Hypertension: Yes	23 (63.9)	30 (78.9)	24 (36.9)	<0.001
Cardiac disease: Yes	6 (16.7)	4 (10.5)	2 (3.1)	0.058*
Diabetes: Yes	1 (2.8)	4 (10.5)	3 (4.6)	0.406*
Liver cysts: Yes	18 (50.0)	21 (55.3)	16 (24.6)	0.003
Cerebral aneurysm: Yes	1 (2.8)	4 (10.5)	0	0.014*
Gout: Yes	9 (25.0)	4 (10.5)	2 (3.1)	0.003*

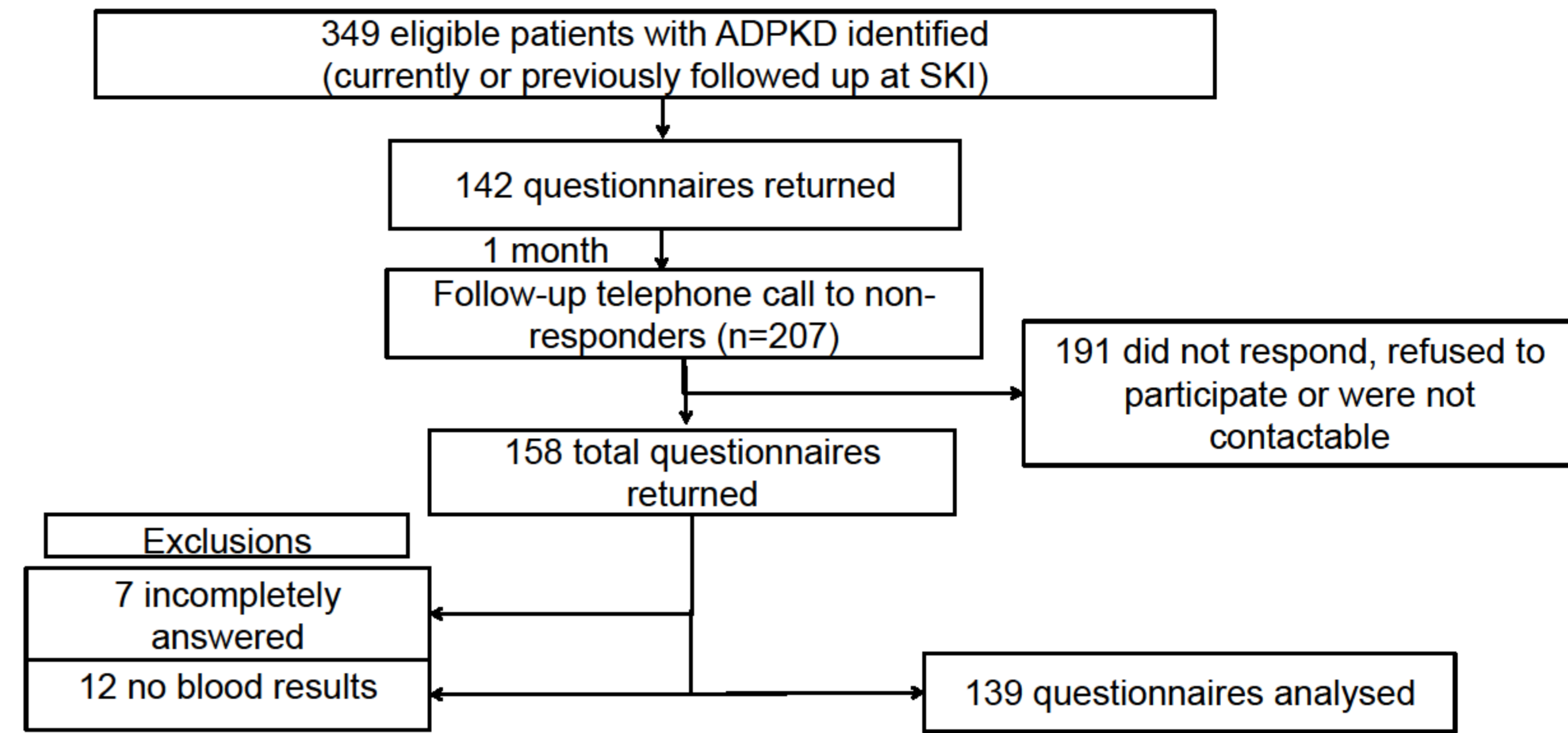
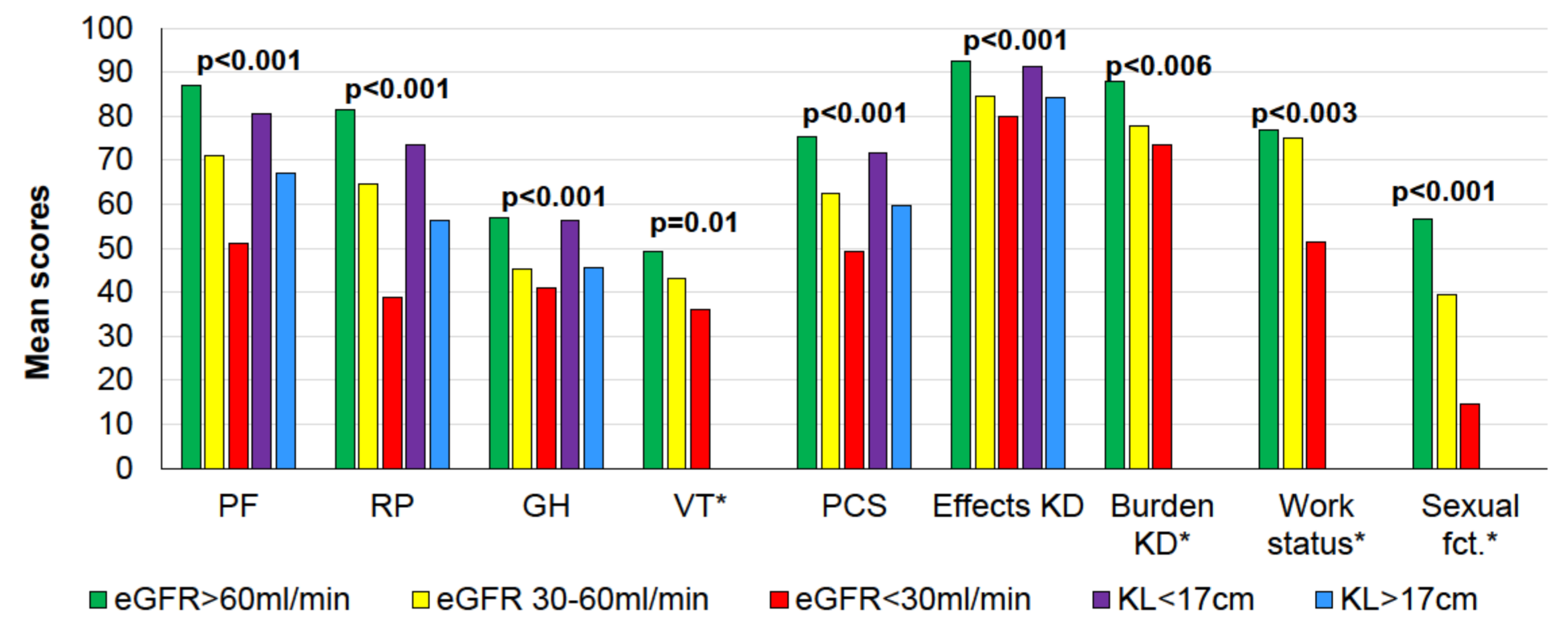


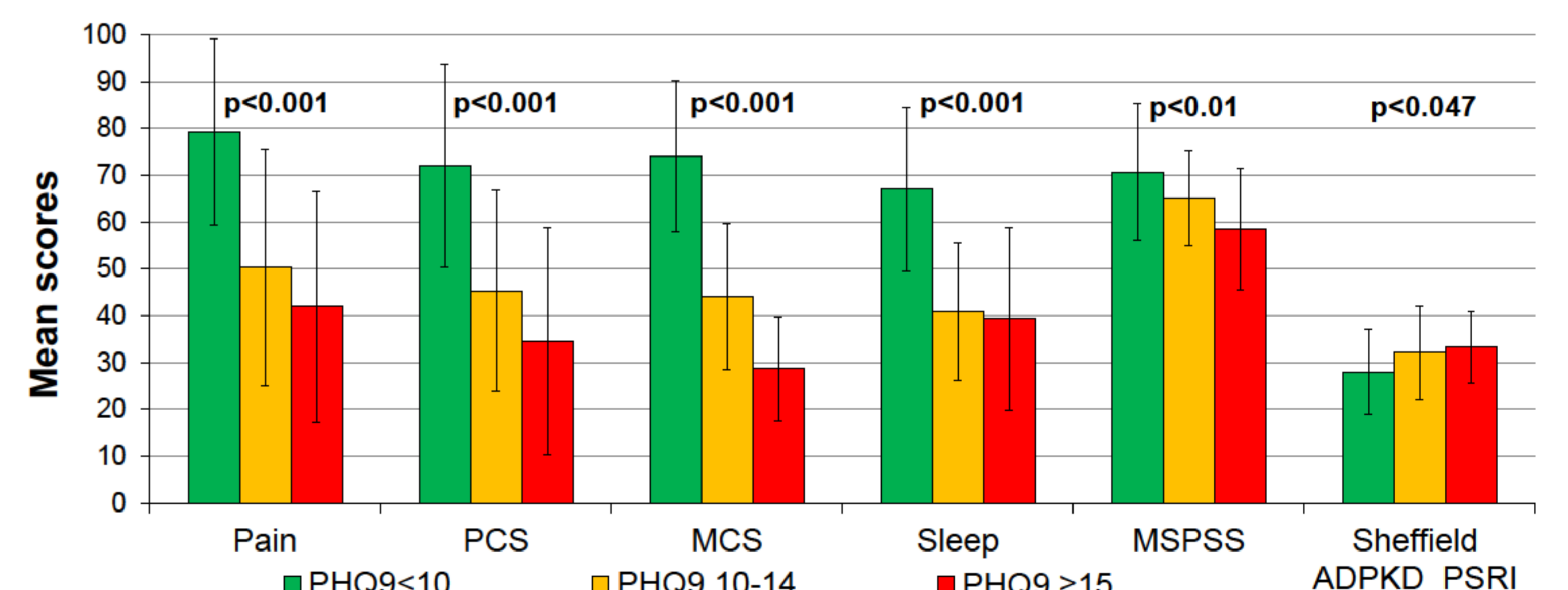
Figure 1 Study outline and identification of patients recruited.

- Significantly worse QOL (lower scores) was reported by patients with lower kidney function or larger polycystic kidneys.



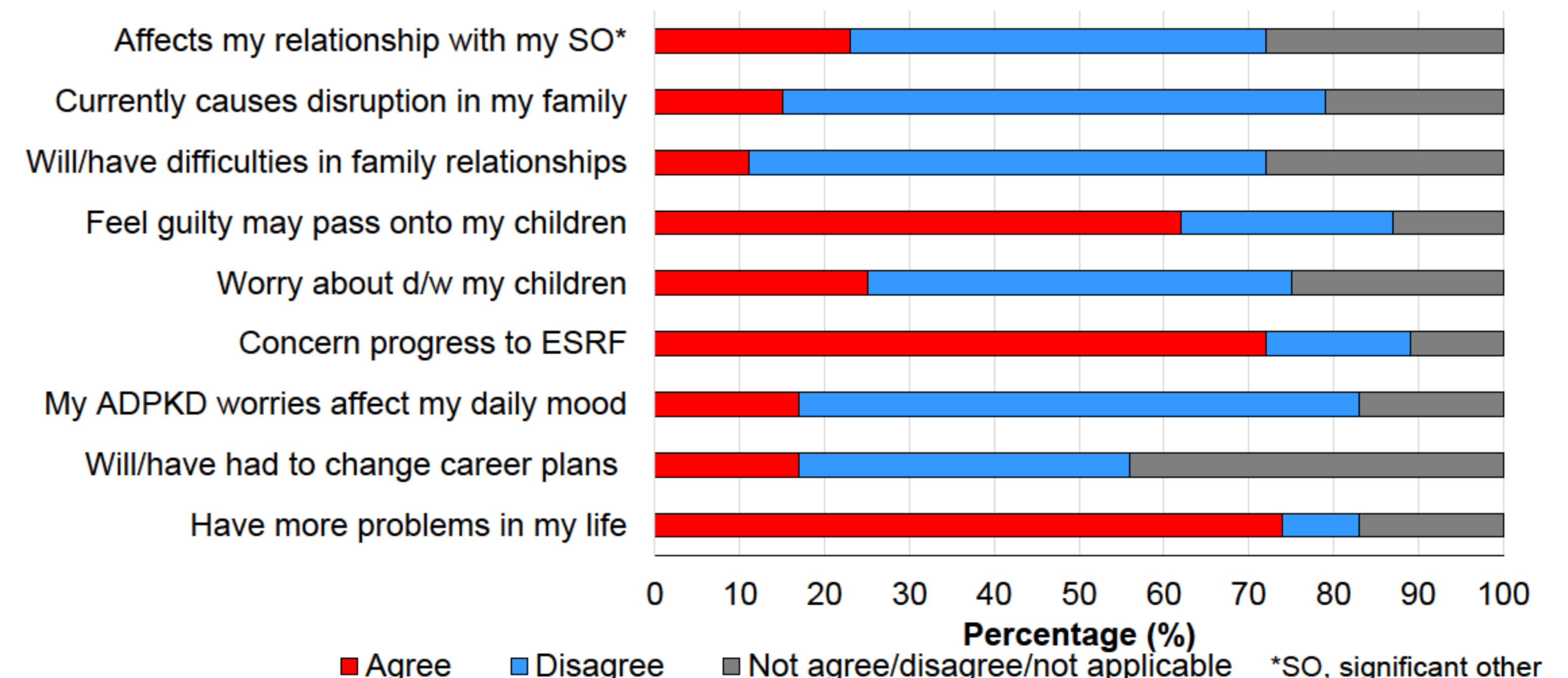
fact., function; GH, general health; KD, kidney disease; PCS, physical component score; PF, physical functioning; RP, role-physical; VT, vitality. *no KL data.

- 22% had clinically significant depression (PHQ9>10).



MSPSS, multidimensional scale of perceived social support; PCS, physical component score; PSRI, psychosocial risk instrument.

- The Sheffield ADPKD PSRI revealed that:
 - 72% worried about progression to kidney failure
 - 62% felt guilty about passing ADPKD on to their children.



Conclusion

- Our study reveals an unexpectedly high rate of depression, poorer quality of life and increased psychosocial risk in European patients with ADPKD prior to starting RRT.
- The future management strategy of ADPKD should address these issues and improve support for patients and their families as they face the challenges of living with ADPKD.