

# D P P P S

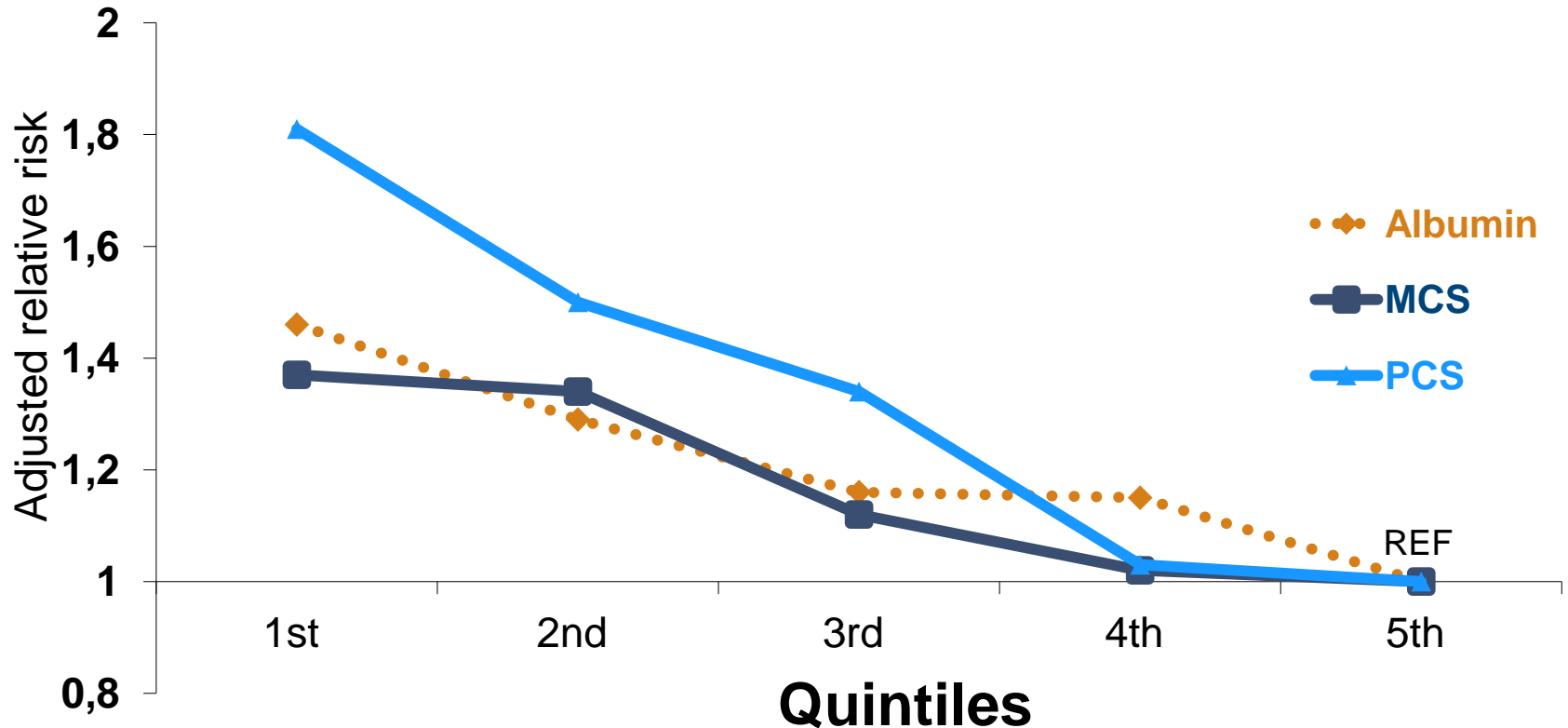
DIALYSIS OUTCOMES AND  
PRACTICE PATTERNS STUDY

## **The patient experience as a key outcome in DOPPS**

**Jennie King RN, BSc (Hons)**

Renal nurse researcher, UK

# We know that the patient *experience* is important

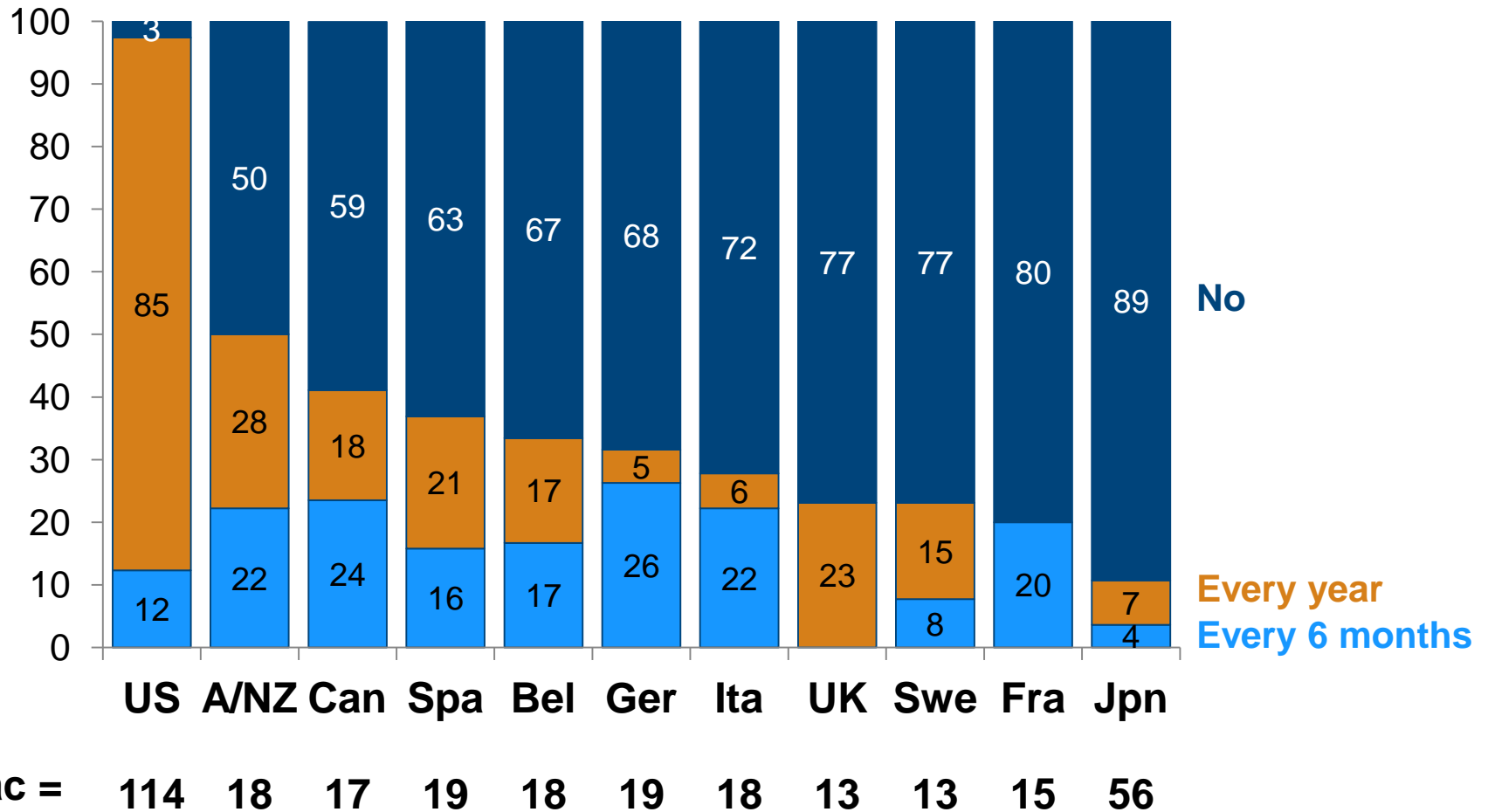


Each line shows a significant trend (each  $P < 0.001$ )

MCS = mental component summary; PCS = physical component summary

# The patient experience is not always investigated by clinicians

% of facilities



DOPPS 4 Unit Practices Survey (2009-11)  
 Question: "Is patient quality of life routinely assessed?"

# **Limitations of current “tools” to assess patients’ experience**

- **Validated instruments that are currently available are long and time-consuming**
- **Too burdensome to be done more than once/twice a year**
- **Only completed by patients who are “healthier” and more willing to spend time doing so**
- **Dialysis patients in the US are reporting “questionnaire fatigue”**

# D P P P S

## DIALYSIS OUTCOMES AND PRACTICE PATTERNS STUDY

AJKD

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Original Investigation

### **Recovery Time, Quality of Life, and Mortality in Hemodialysis Patients: The Dialysis Outcomes and Practice Patterns Study (DOPPS)**

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Hal Morgenstern, PhD,<sup>2,3,4</sup> Angelo Karaboyas, MS,<sup>2</sup> Bruce F. Culleton, MD,<sup>5</sup>  
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Manfred Hecking, MD,<sup>10</sup> Ronald L. Pisoni, PhD,<sup>2</sup> and Bruce M. Robinson, MD<sup>2,7</sup>*

# Recovery Time Question

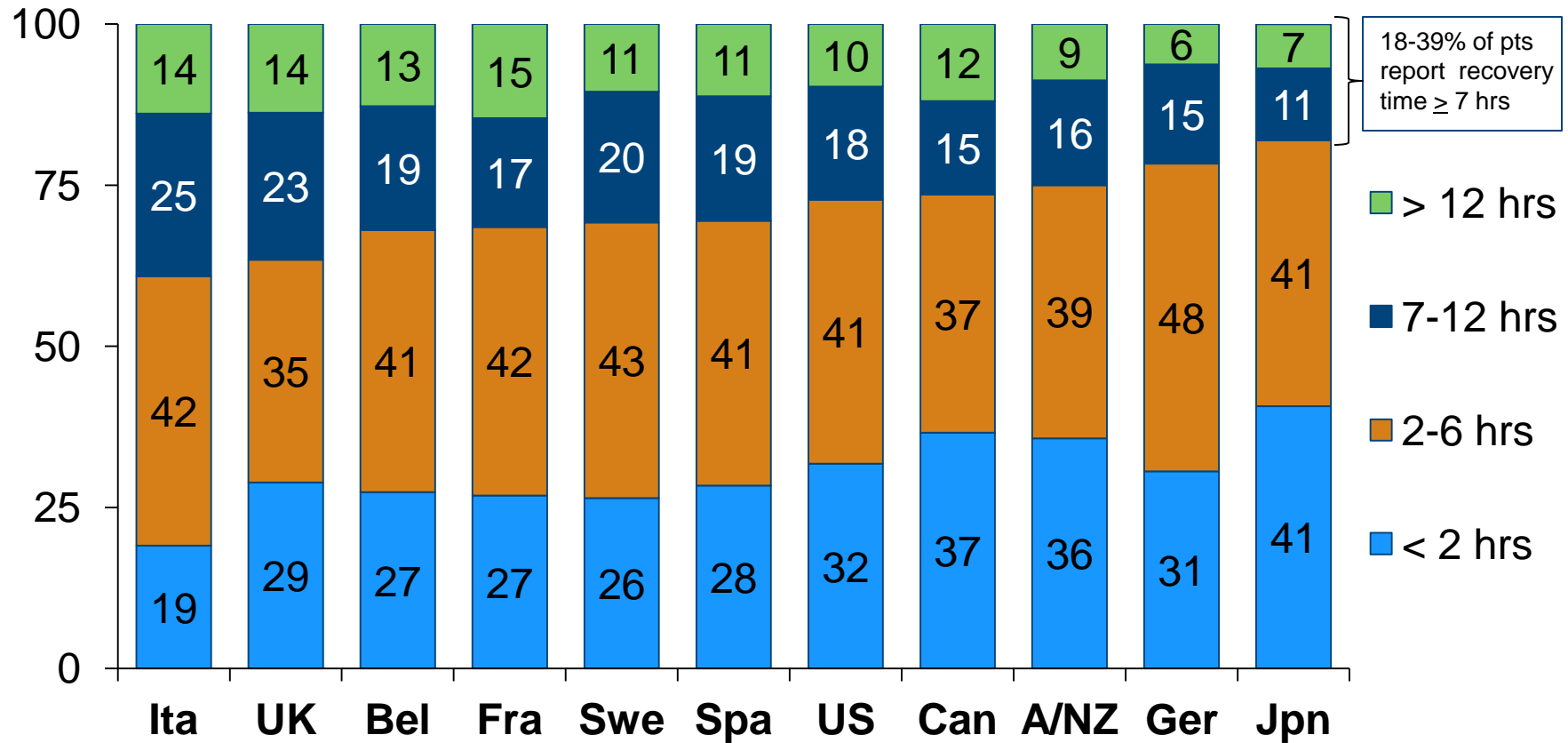
A-13\*\* How long does it take you to recover from a dialysis session?

- Less than 2 hours .....  1
- 2-6 hours .....  2
- 7-12 hours .....  3
- Greater than 12 hours .....  4

\*\* Adapted from: Lindsay R. M., Heidenheim P. A., Nesrallah G., Garg A. X., Suri R. Minutes to recovery after a hemodialysis session: a simple health-related quality of life question that is reliable, valid, and sensitive to change. *Clinical Journal of the American Society of Nephrology*. 2006; 1:952-9.

# Self-Reported Recovery Time

% of Patients

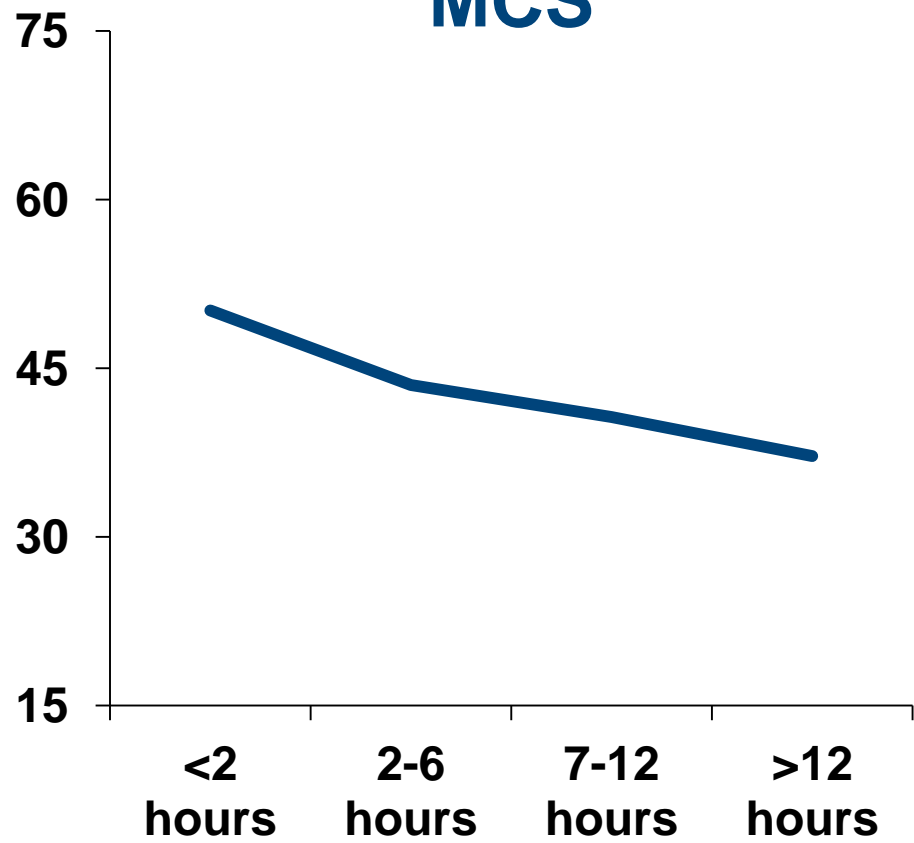


N Patients: 252 369 268 343 448 483 1513 419 276 298 1371

# Longer recovery time is correlated with lower quality of life

Median Score

**MCS**

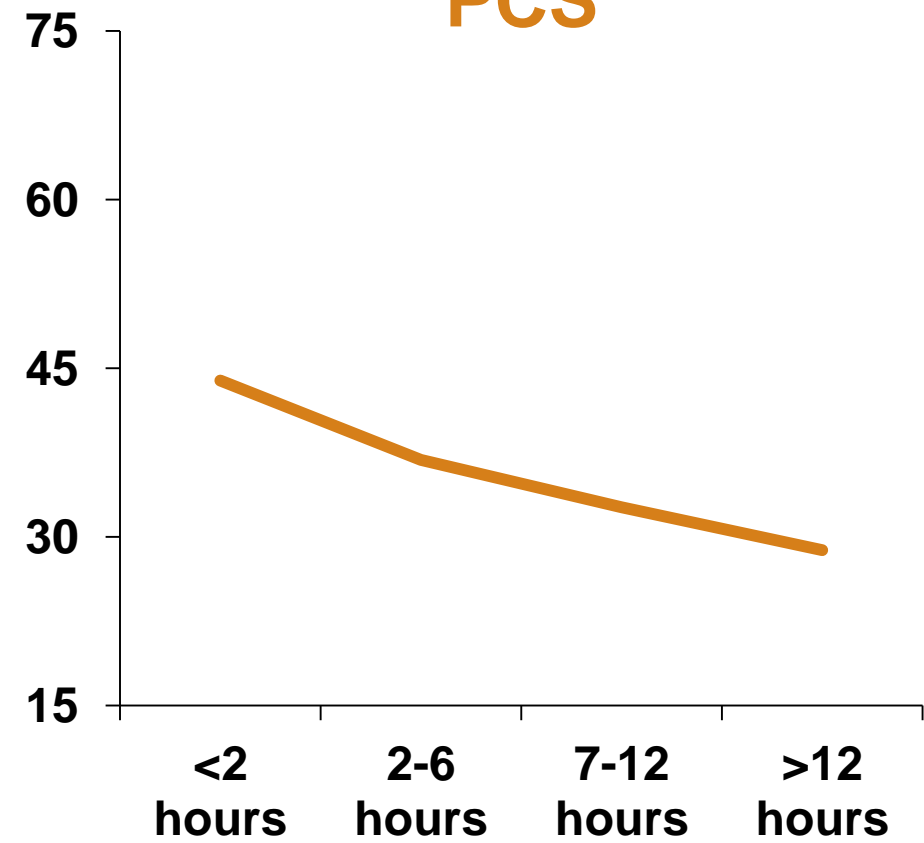


Patient N = 1299      1651      675      363

**Patient-reported Recovery Time**

Median Score

**PCS**



Patient N = 1303      1660      683      377

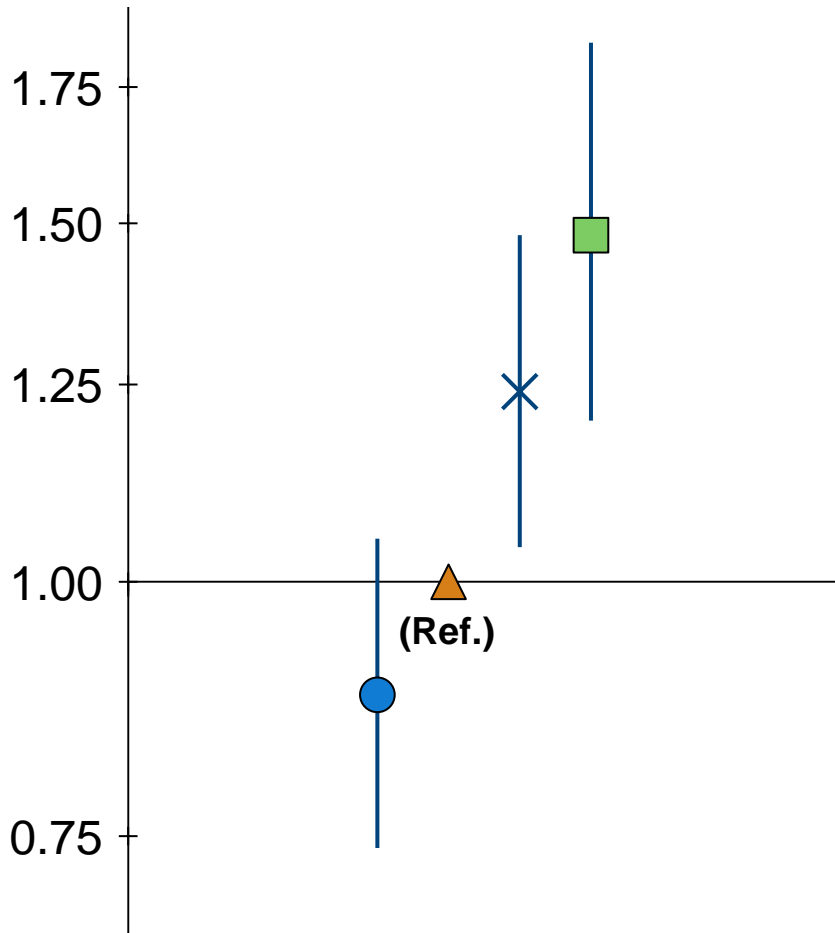
**Patient-reported Recovery Time**

DOPPS 4 Patient Questionnaire  
MCS=Mental Component Summary; PCS=Physical Component Summary

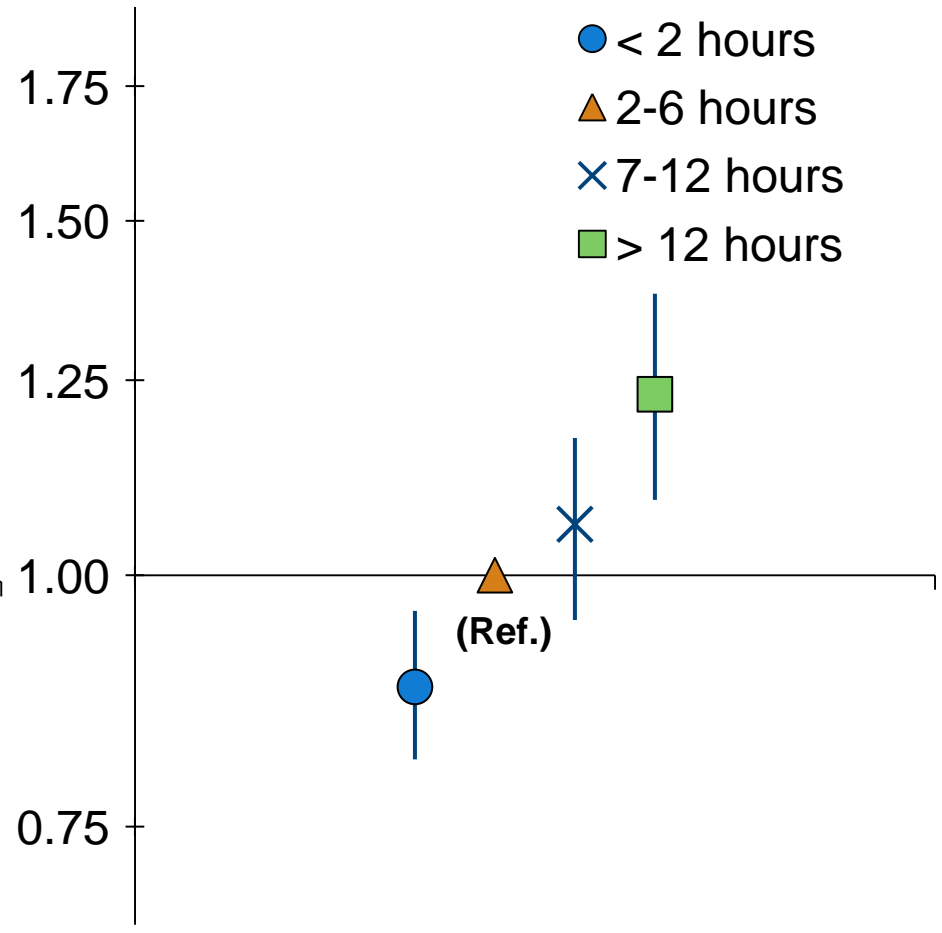


# Recovery Time and Mortality/Hospitalization

## HR (95% CI) for mortality



## HR (95% CI) for first hospitalization



Cox models stratified by country and race (US black only) and use a robust "sandwich" variance estimator;  
Demographic adjustments: sex, age, time on dialysis, BMI, and 14 summary comorbidities;  
HR-QOL adjustments: RAPA, depression, sleep problems, pruritus, ADL count, employment, PCS, MCS

Rayner et al. *Am J Kidney Dis* 64(1):86-94, 2014

# Work Remains to Be Done

- **There is an opportunity to develop questions to facilitate routine assessment of patients' experience in dialysis care**
- **They should be simple, easy to understand and to ask at every round**
- **Must be based on factors patients identify as important**

**What factors are important to dialysis patients?**

# Beyond survival, what else?

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Patients

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Rank	Pre-dialysis	Pre-dialysis	PD	HD
1	Keeps patient alive (survival)	Keeps patient alive (survival)	Convenience (dialysis at home)	Keeps patient alive (survival)
2	Dialysis-free days	Flexible schedule	Keeps patient alive (survival)	Better health (patient)
3	Convenience (dialysis at home)	Ability to travel	Self-management (independence)	Dialysis-free days

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DIALYSIS OUTCOMES AND  
PRACTICE PATTERNS STUDY

**Hemodialysis Patient Preference for  
Type of Vascular Access:  
Variation and Predictors Across Countries in the DOPPS**

**Rachel B. Fissell, MD; Douglas S. Fuller, MS; Hal Morgenstern, PhD; Brenda W. Gillespie, PhD; David C. Mendelssohn, MD; Hugh C. Rayner, MD; Bruce M. Robinson, MD; Dori Schatell, MS; Hideki Kawanishi, MD; Ronald L. Pisoni, PhD**

*Journal of Vascular Access* 2013 Oct 1;14(3):264-72.

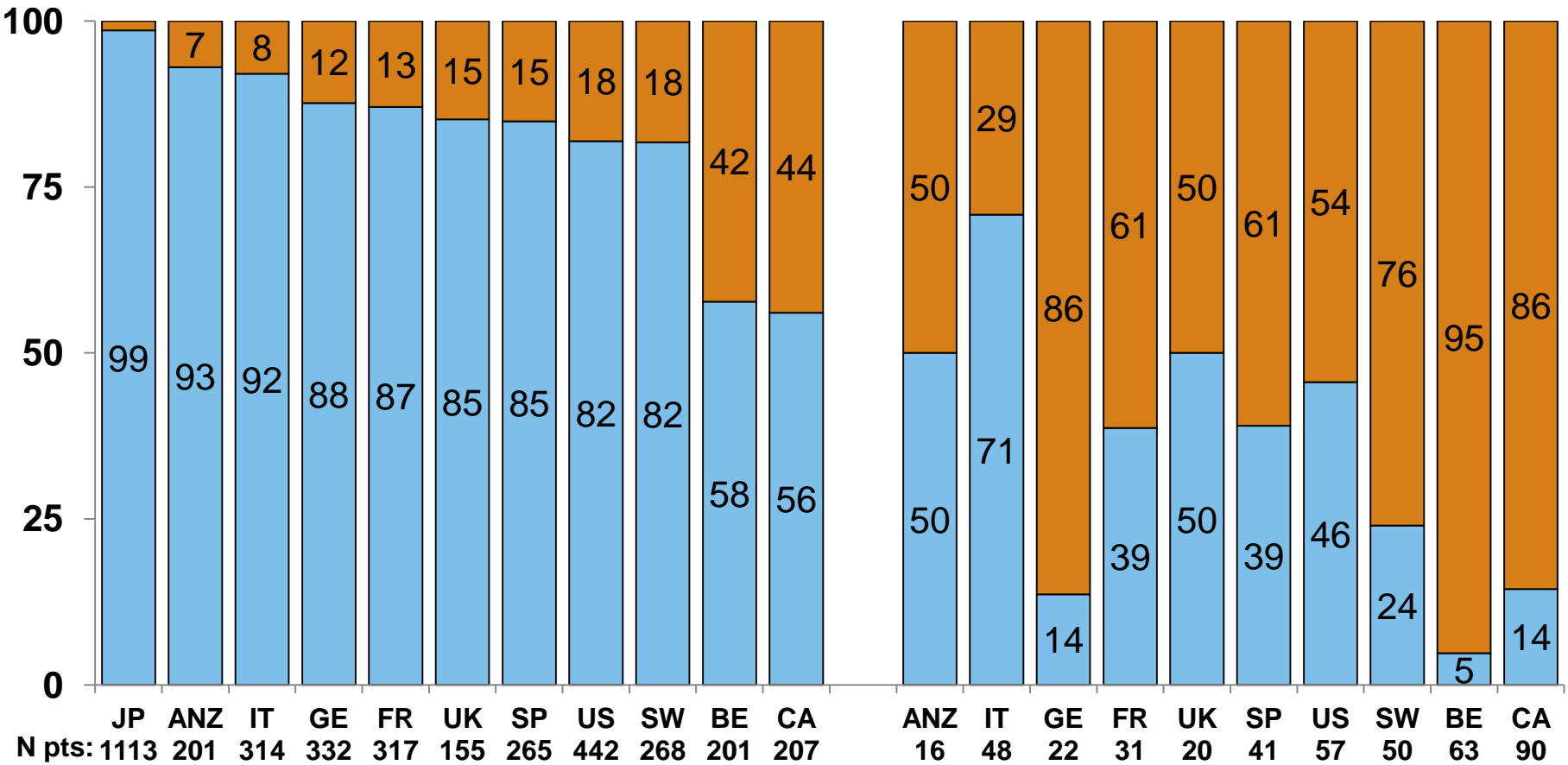
# Patient indication of preference for either catheter or an AV fistula or graft, by country

■ Prefer Fistula or Graft    ■ Prefer Catheter

% patients

All Patients

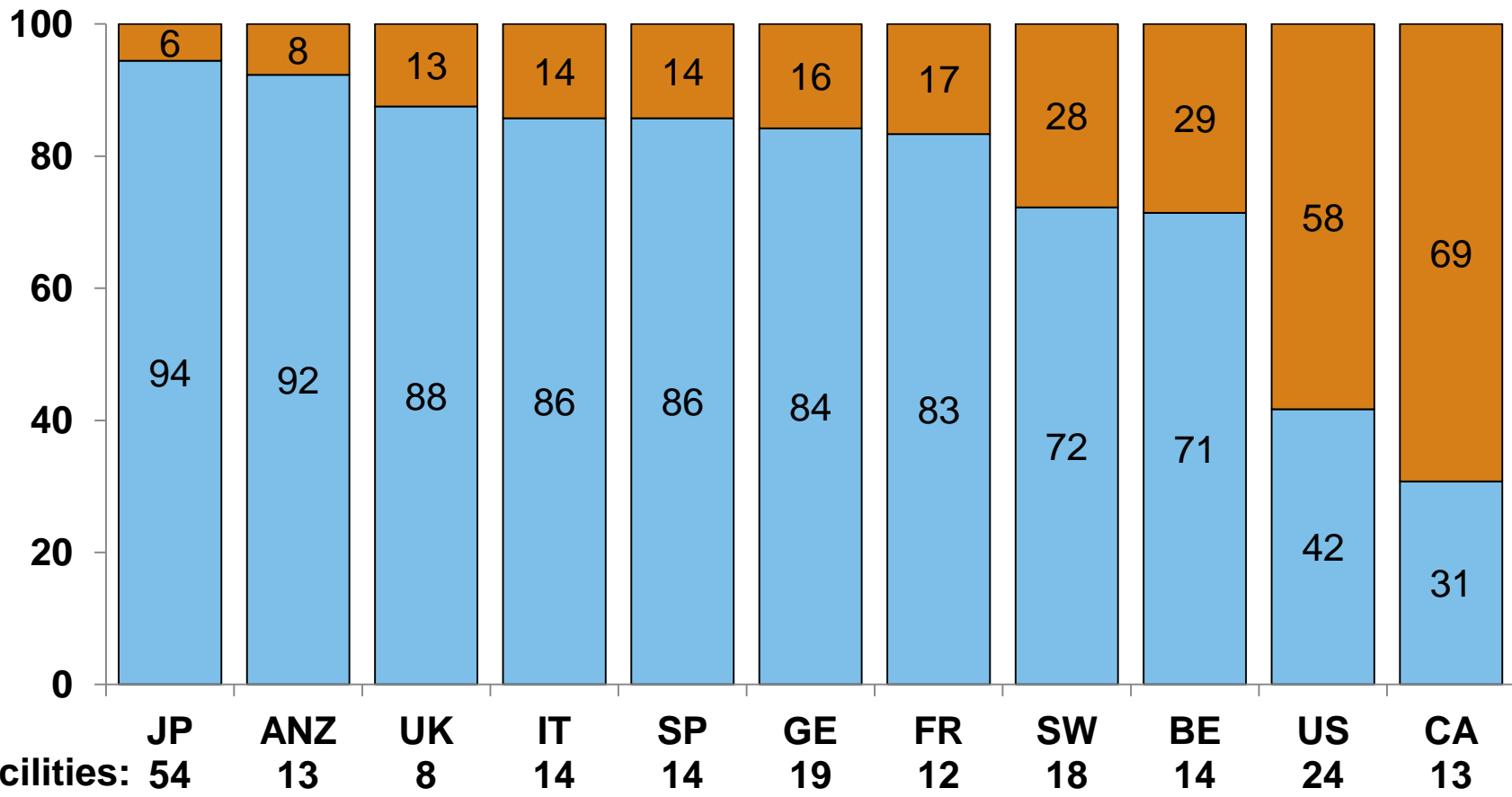
Patients currently using a catheter



# Medical Director indication of “Patient Preference” as reason for use of permanent catheter as primary vascular access

% facilities in country

Never or rarely      Sometimes, often, or always



# **Key points & Take home message**

**Patient experience is important to them and should be to us..**

**Patients need a have 'a voice' / opportunity**

**Design simple, relevant Qs**

**What could be better in your patients' lives?**