



# STRATEGIES FOR “CONSERVATIVE” (SUPPORTIVE) MANAGEMENT OF RENAL FAILURE

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# Disclosure of Interests

- Steering committee - ASCEND study
- Janssen – National leader, Credence study
- Amgen – educational grant

KDIGO



# Agenda

- Concept of KSP and CC
- Guideline recommendations for CC
- Barriers for implementation of CC
- Recommendations (education, research, advocacy)
- Strategies for implementing KSC and CC in HIC and LMIC



**Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care**

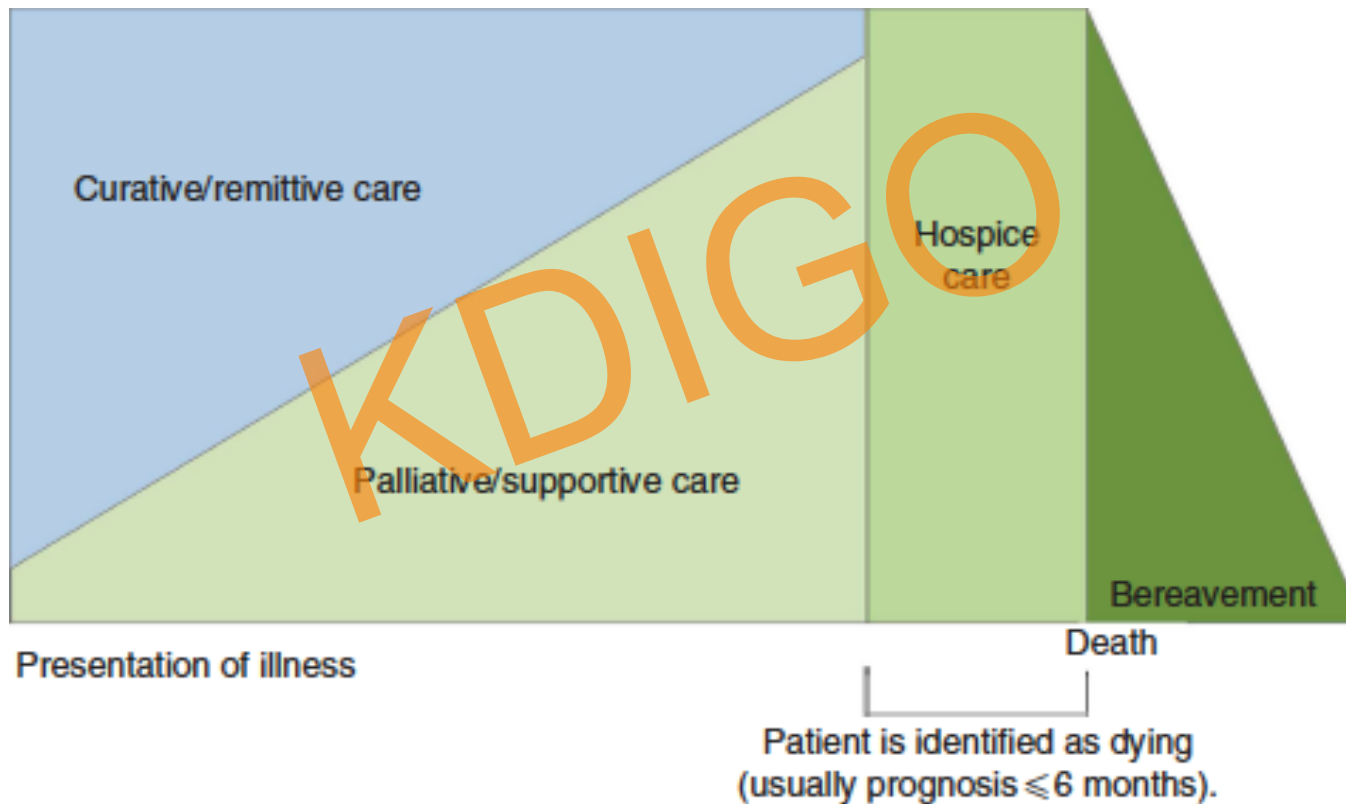
*Kidney International* (2015) **88**, 447–459

- **Kidney supportive care (KSC)** involves services that are aimed at improving the HRQOL for patients with established CKD, at any age, and can be provided together with therapies intended to prolong life, such as dialysis
- Supportive care helps patients cope with living, as well as dying, regardless of life expectancy
- Hospice/terminal care shares the same philosophy, but it is under the larger umbrella of supportive care, and it is typically limited to patients who are believed to be within months of death



# Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

*Kidney International* (2015) **88**, 447–459



# KDIGO Recommendations

- To optimally deliver **kidney supportive care**, multiprofessional renal teams should do the following:
  - Identify those patients who are most likely to benefit from supportive care interventions
  - Assess and manage symptoms effectively
  - Estimate and communicate prognosis (survival and future illness trajectory) to the best of their ability
  - Develop appropriate goals of care that address individual patients' preferences, goals, and values
  - Possess knowledge of, and experience with, available local supportive care services, and be aware of when and how to refer
  - Assist with care coordination including referral to specialist supportive care and hospice service as available and appropriate

Kidney Int 2015;88:447–459

*KDIGO Controversies Conference on Advanced CKD | December 2-5, 2016 | Barcelona, Spain*



**Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care**

*Kidney International* (2015) **88**, 447–459

Comprehensive conservative care (CCC) is planned holistic patient centered care for patients with G5 CKD that includes the following:

- Interventions to delay progression of kidney disease and minimize risk of adverse outcomes
- Shared decision making
- Active symptom management
- Detailed communication including advance care planning
- Psychological support
- Social and family support
- Cultural and spiritual domains of care

**CCC does not include dialysis**



# CC Populations

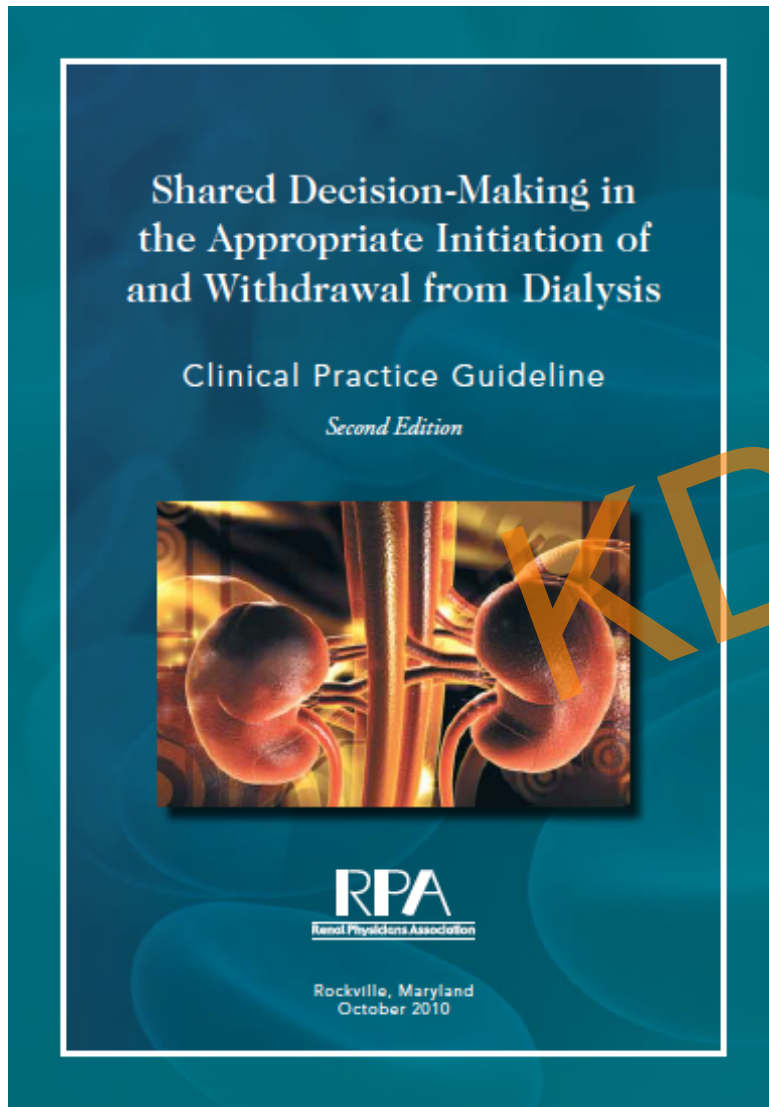
- Comprehensive conservative care
  - CC that is chosen or medically advised
- Choice-restricted conservative care
  - CC for patients in whom resource constraints prevents or limit access to RRT; therefore, a choice for CC cannot be recognized
- Unrecognized G5 CKD
  - CKD is present but has not been recognized or diagnosed; therefore, a choice for CC cannot be that is chosen or medically advised

Kidney Int 2015;88:447–459





# RPA's Clinical Practice Guideline



The RPA's CPG recommend to inform patients with CKD 4 or 5 and patients with ESRD about their prognosis and all treatment options, including conservative care

# KDIGO Recommendations

- Primary **supportive care** should be available to all patients with advanced CKD and their families throughout the entire course of their illness
- **CCC** should be provided as a viable, quality treatment option for patients who are unlikely to benefit from dialysis

Kidney Int 2015;88:447–459



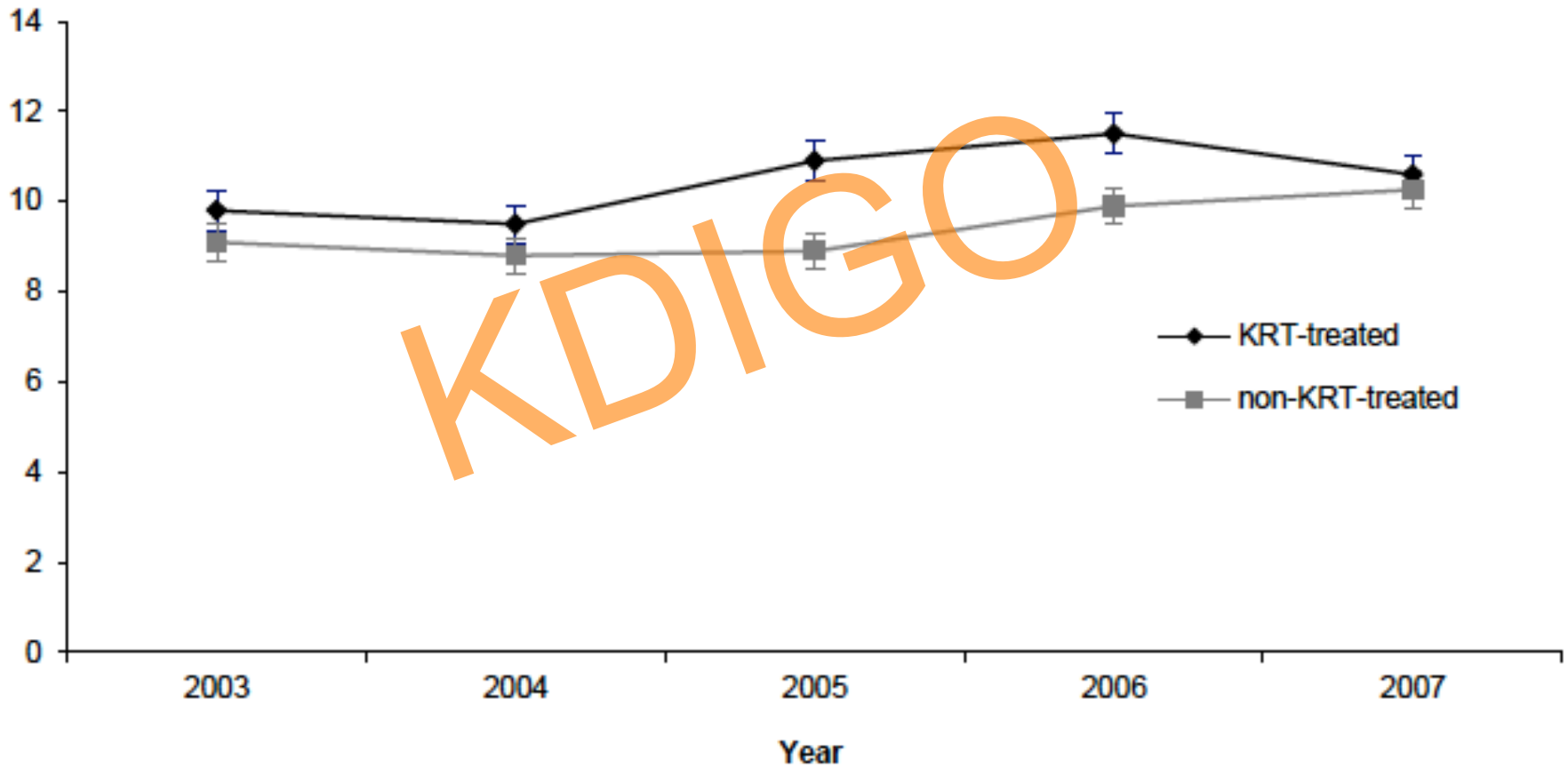


Australian Government  
Australian Institute of  
Health and Welfare

# End-stage kidney disease in Australia

## Total incidence, 2003–2007

Number per 100,000

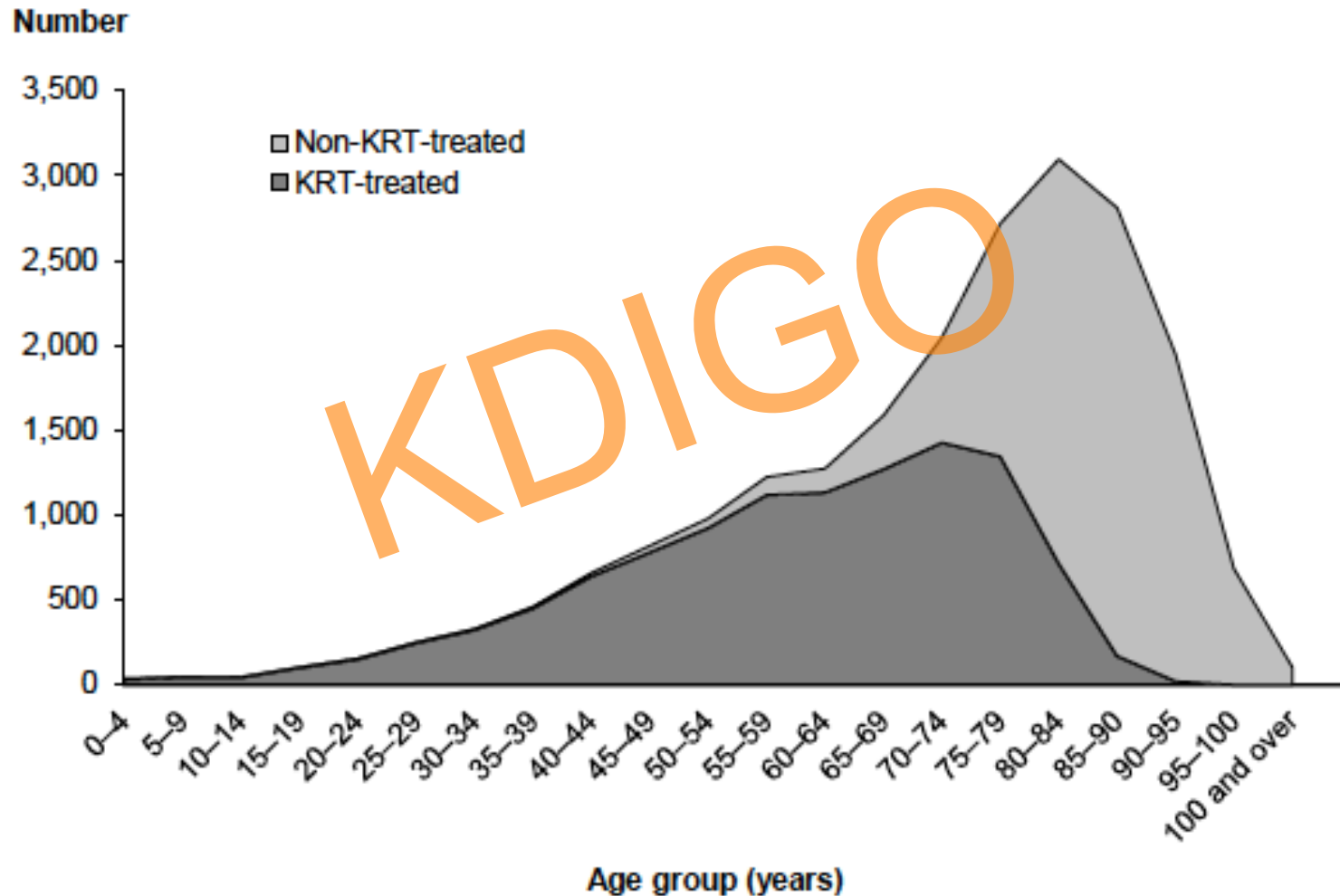




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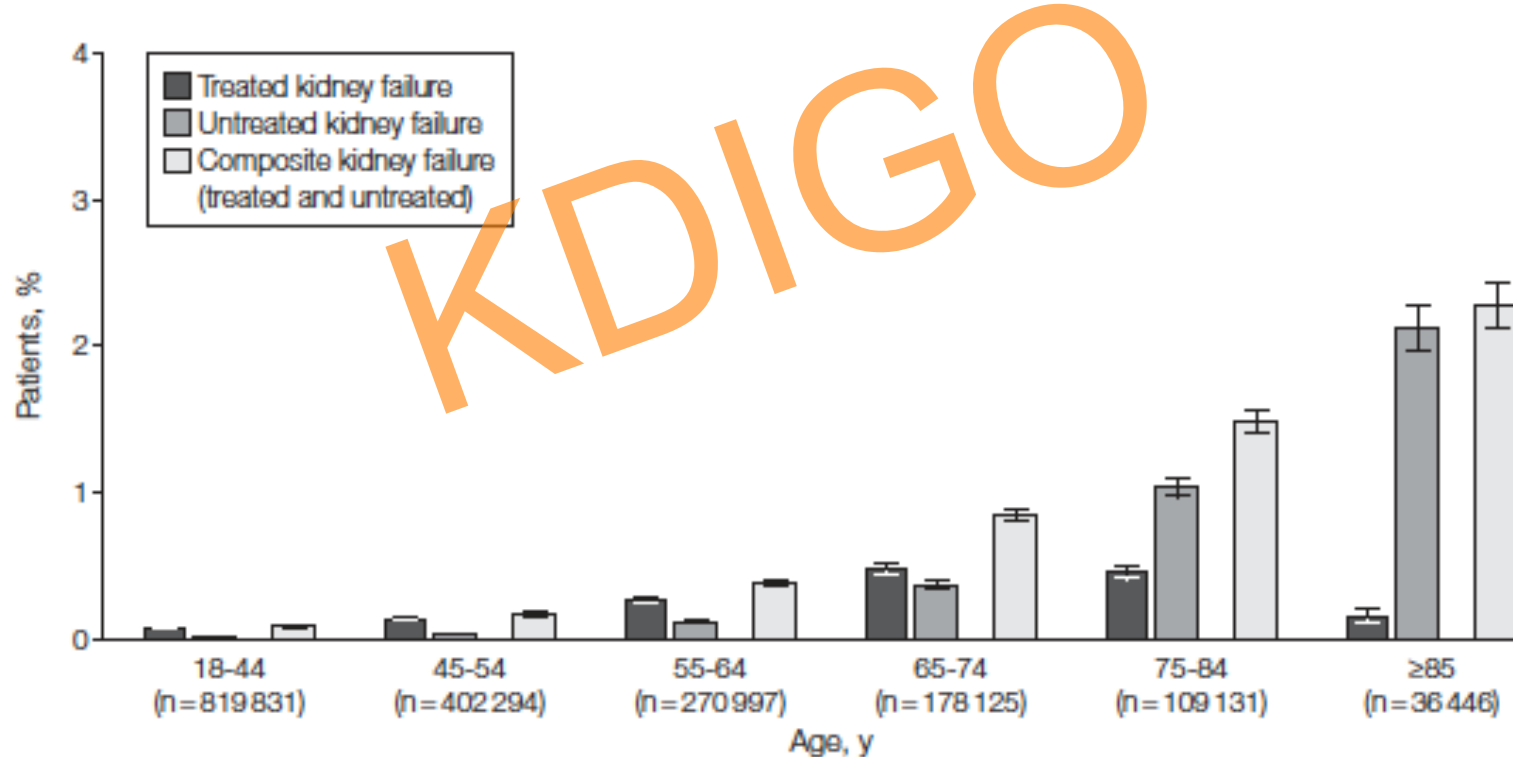


KDIGO



# Rates of Treated and Untreated Kidney Failure in Older vs Younger Adults

- 1,816,824 patients from Alberta, Canada with eGFR >15 ml/min
- 4.4 years of median follow up
- **0.17%** progressed to treated kidney failure
- **0.18%** progressed to kidney failure and were managed conservatively



JAMA, June 20, 2012—Vol 307, No. 23



# Barriers for Implementation of CC

- Lack of a precise definition of CC
- Poor characterization of the CKD population that might benefit from CC
- Limited observational evidence of its potential benefits
- Scarce data on patient-centered outcomes
- Imprecise prognostic tools
- Lack or insufficient education regarding CC (and RSC)

*Clin J Am Soc Nephrol 11: 750–752, 2016*



# Conservative Care for ESRD in the United Kingdom: A National Survey

- The absolute number of patients could not be calculated because of **lack of agreement** on when a patient is receiving CC
- **Terminology** varied substantially among renal units, with CM being the most frequently used term (46%)
- 80% of units reported a need for better evidence comparing **outcomes** of CC versus dialysis
- 65% considered appropriate to enter patients into a **RCT**

*Clin J Am Soc Nephrol* 10: 120–126, 2015



## Provider Knowledge, Attitudes, and Practices Surrounding Conservative Management for Patients with Advanced CKD

- Nation-wide US survey to examine nephrologists' and PCPs' practices, attitudes, and knowledge regarding CC
- Confusion about terminology
  - >40% of both nephrologists and PCPs believed that CC and palliative care were the same
- Lack of knowledge about CC
  - 20%-30% of nephrologists and PCPs responded that CC could serve as a bridge to kidney transplantation

*Clin J Am Soc Nephrol* 11: 812–820, 2016





## Provider Knowledge, Attitudes, and Practices Surrounding Conservative Management for Patients with Advanced CKD

- Both NEPH and PCP reported similar practices about discussing CC with their patients (61% versus 54.3%)
- There were significant differences regarding barriers to discussing CC
  - Difficulty in determining eligibility (14.3% NEPH versus 42.5% PCP)
  - Limited information about its effectiveness (24.5% NEPH versus 49.6% PCP)

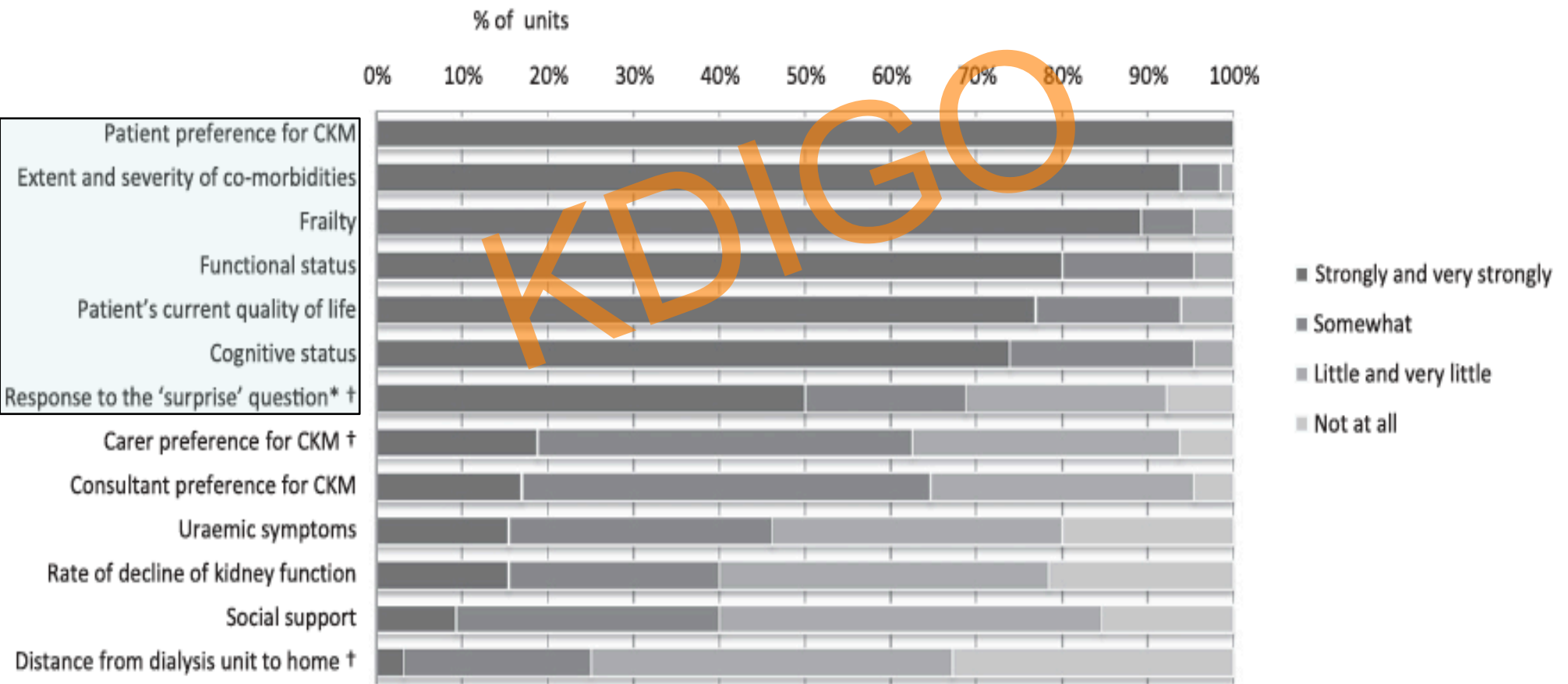
*Clin J Am Soc Nephrol* 11: 812–820, 2016



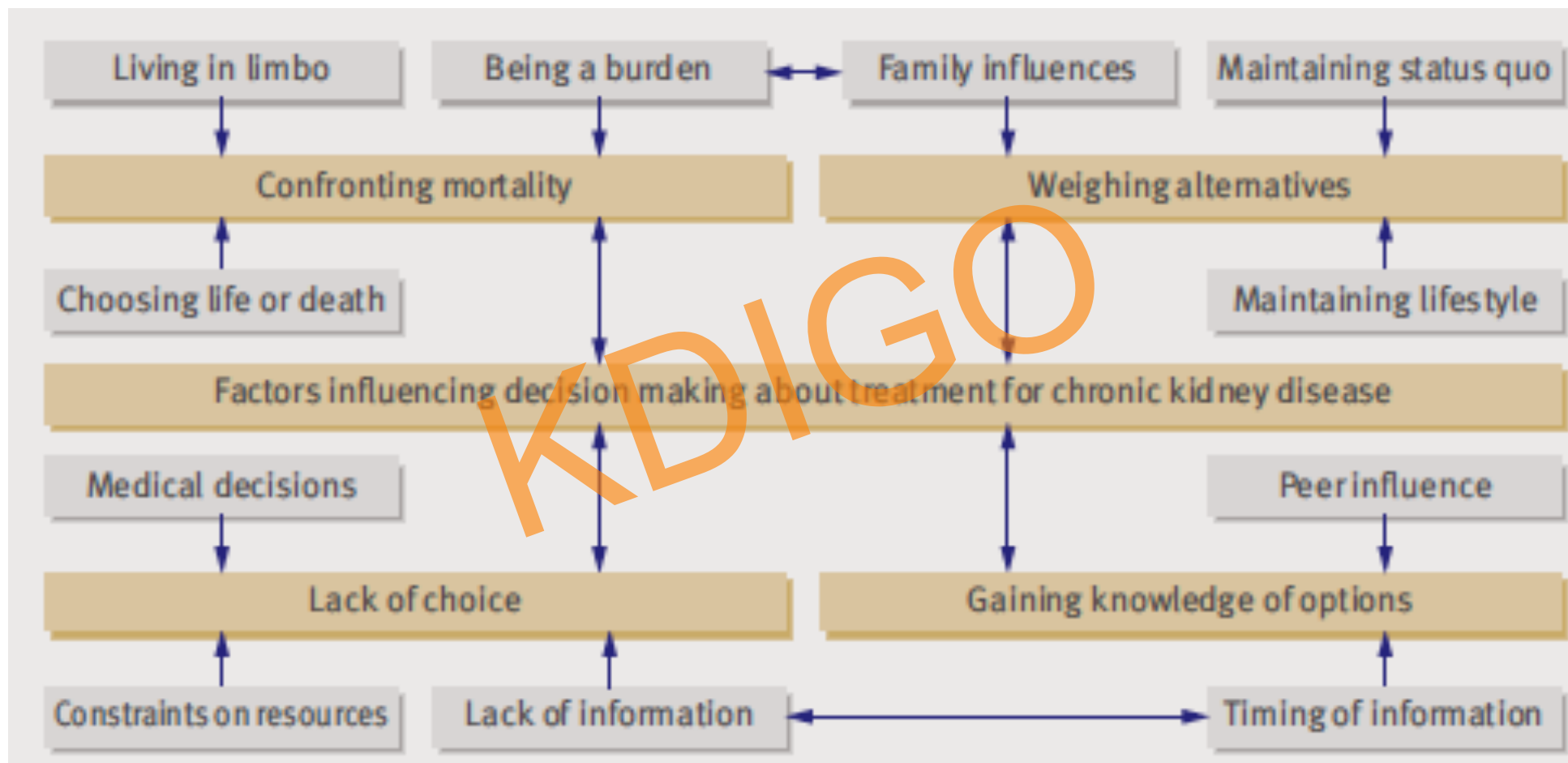
# Conservative Care for ESRD in the United Kingdom: A National Survey

*Clin J Am Soc Nephrol* 10: 120–126, 2015

**Which of the following factors are likely to influence staff when contemplating the suitability of CC for a patient?**



# The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies



BMJ 2010;340:c112



# Understanding by Older Patients of Dialysis and Conservative Management for Chronic Kidney Failure

Table 1. Numbers of Patients Recruited From Each Management Pathway and Each Renal Unit

Renal Unit No.	Predialysis	Dialysis	CM Pathway	Total for Renal Unit
1	2	1	2	5
2	2	2	2	6
3	2	1	1	4
4	1	2	1	4
5	3	2	1	6
6	1	3	1	5
7	2	1	1	4
8	0	1	3	4
9	1	1	2	4
Total	14	14	14	42

- Patients who had chosen different treatments held **varying beliefs** about what dialysis could offer
- The **information** that patients reported receiving from clinical staff differed between **units**
- Patients from units with a more established **CC pathway** were more aware of CC, less often believed that dialysis would guarantee longevity, and more often had discussed the future with staff
- Some patients receiving CC reported that they would have **dialysis** if they became unwell in the future

*Am J Kidney Dis.* 65(3):443-450



# Conservative Management of End-Stage Renal Disease without Dialysis: A Systematic Review

- 7 cohort studies about **prognosis**, 4 prospective with reasonable follow-up
- Median survival with CC ranged from 6.3 to 23.4 months
- 5 studies included a comparison group of patients on dialysis
  - One found a modest survival benefit that disappeared with higher comorbidity (particularly ischemic heart disease)
  - One reported no statistically significant benefit
  - The remaining 3 studies reported a significant survival benefit with dialysis

J Pall Care 2012;15:228–235



# Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5

Fliss E. M. Murtagh<sup>1</sup>, James E. Marsh<sup>2</sup>, Paul Donohoe<sup>3</sup>, Nasirul J. Ekbal<sup>4</sup>, Neil S. Sheerin<sup>5</sup> and Fiona E. Harris<sup>2</sup>

Nephrol Dial Transplant (2007) 22: 1955–1962

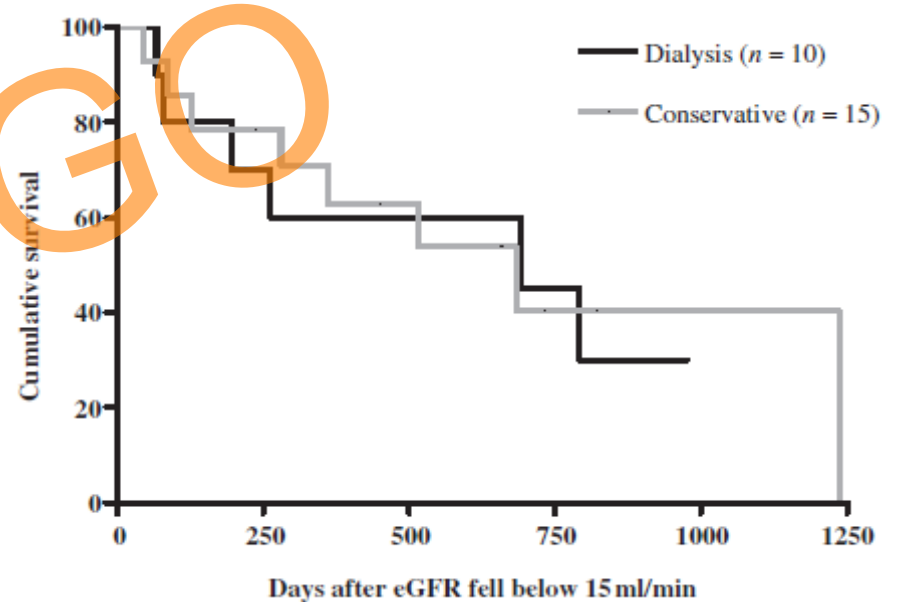
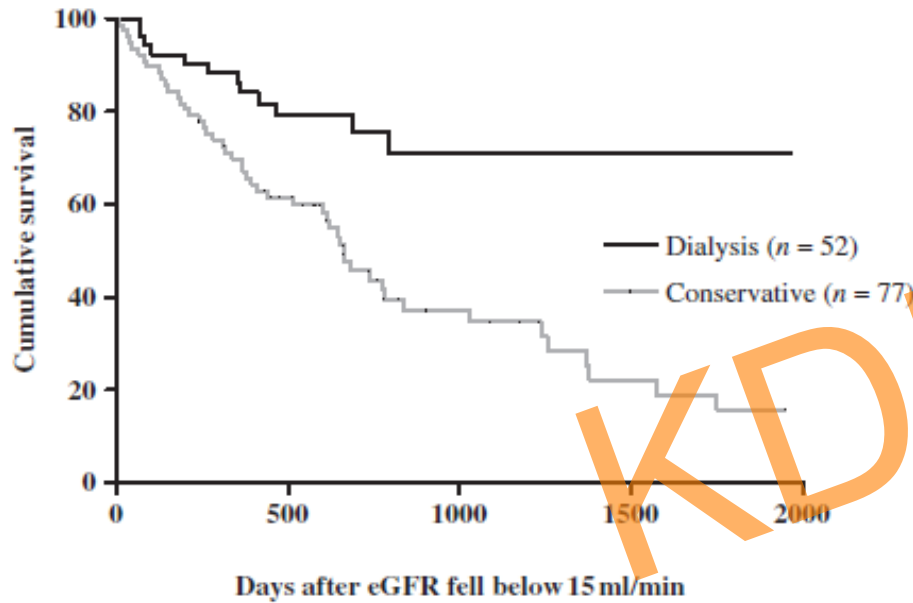


Table 2. One- and two-year survival rates

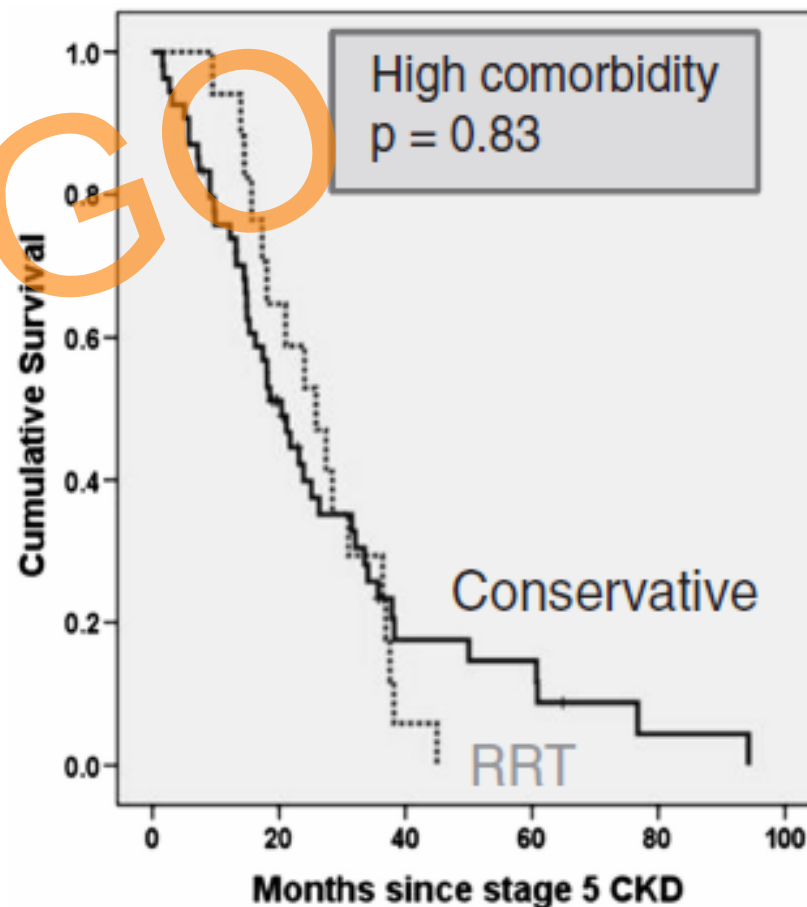
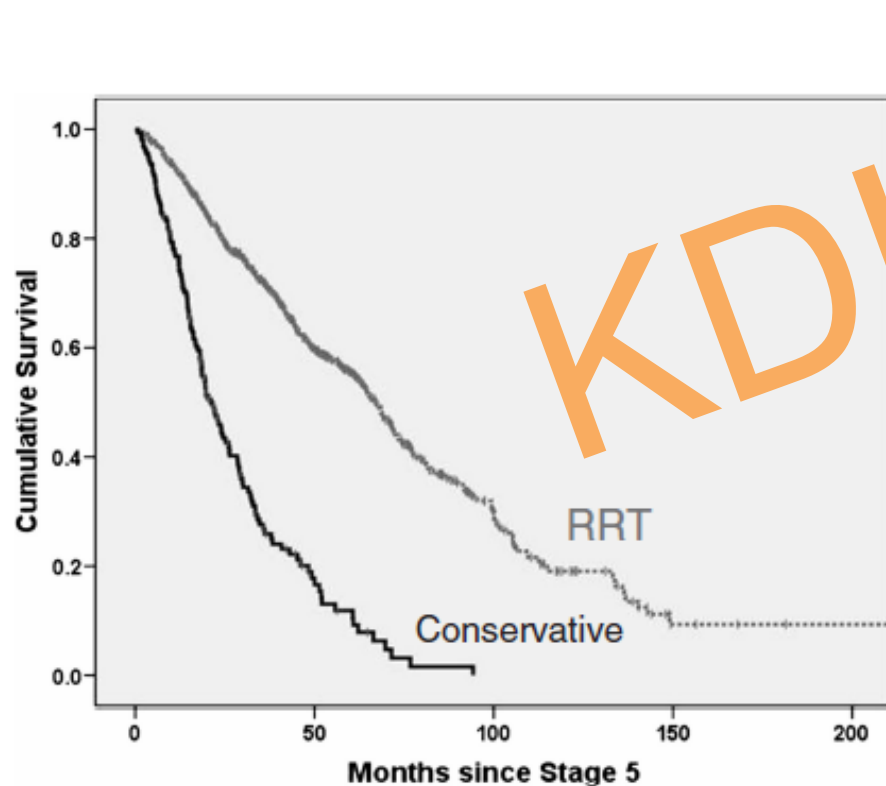
	Dialysis group	Conservative group	All patients
1 year survival rate	84%	68%	74%
2 year survival rate	76%	47%	58%



# Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy

Shahid M. Chandna, Maria Da Silva-Gane, Catherine Marshall, Paul Warwicker, Roger N. Greenwood and Ken Farrington

Nephrol Dial Transplant (2011) 26: 1608–1614



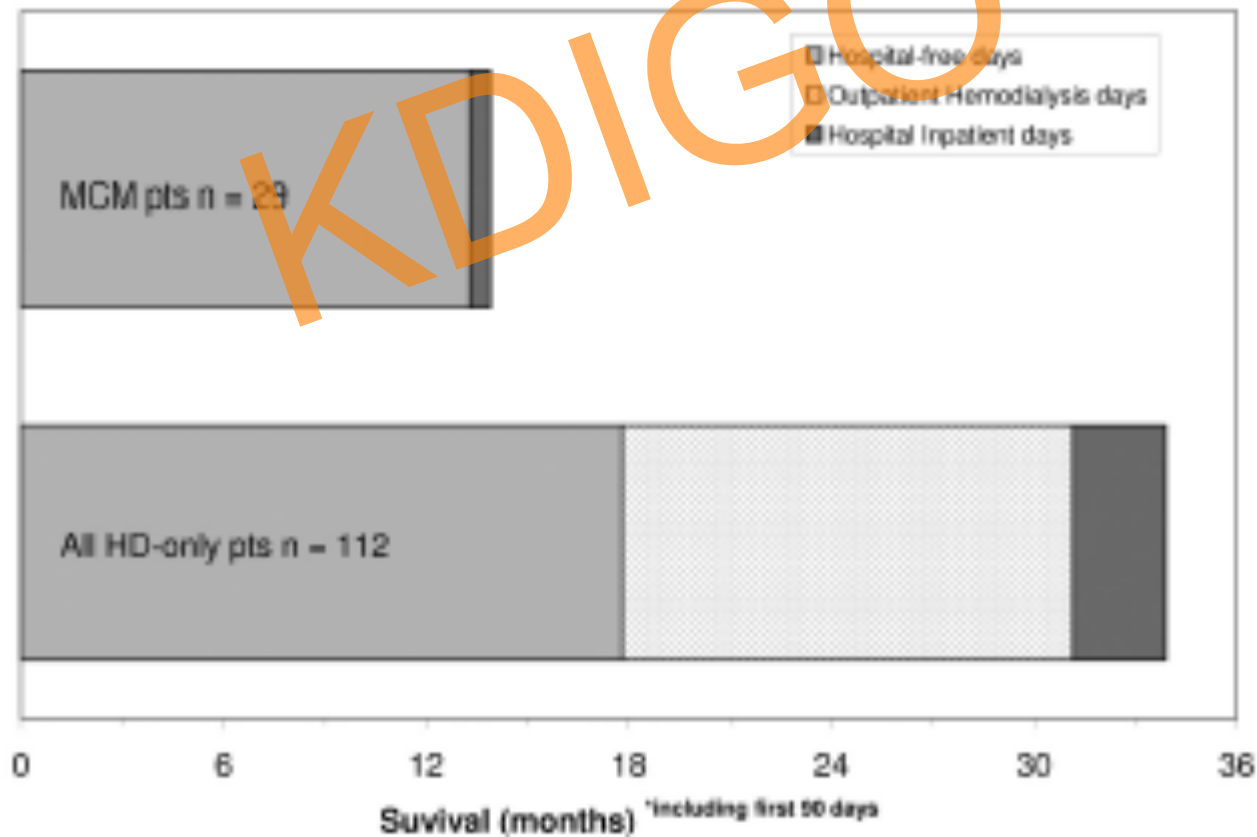
# Is Maximum Conservative Management an Equivalent Treatment Option to Dialysis for Elderly Patients with Significant Comorbid Disease?

Rachel C. Carson,\* Maciej Juszcak,<sup>†</sup> Andrew Davenport,<sup>†</sup> and Aine Burns<sup>†</sup>

\*Nanaimo Regional Hospital, Nanaimo, British Columbia, Canada; and <sup>†</sup>UCL Center for Nephrology, Royal Free and University College Medical School, Hampstead Campus, London, United Kingdom

*Clin J Am Soc Nephrol* 4: 1611–1619, 2009

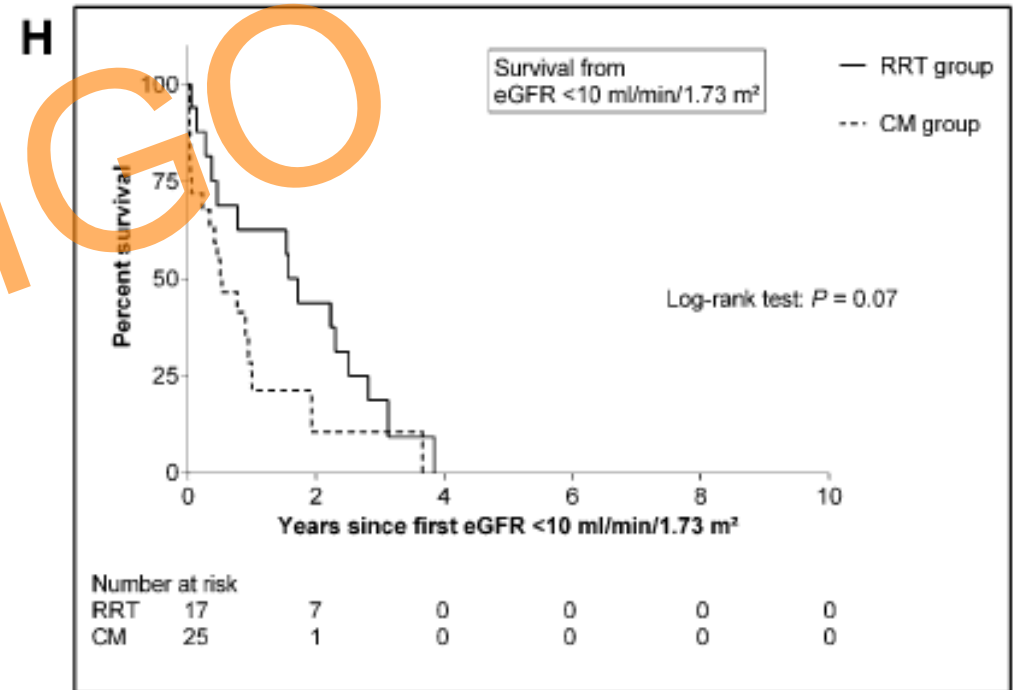
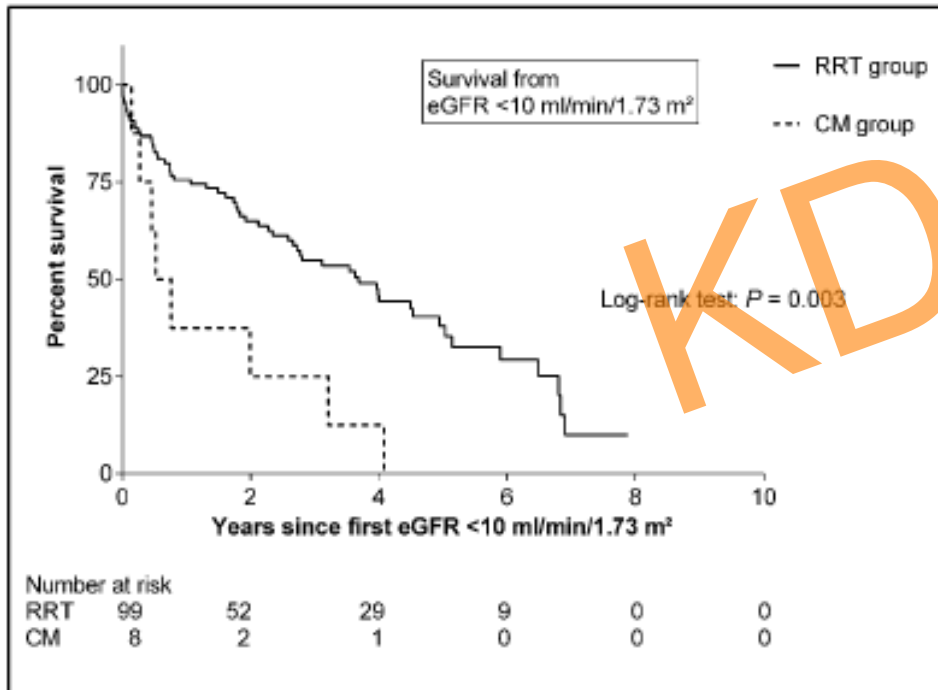
Distribution of Days Survived:  
Hospital-free Days, Outpatient Hemodialysis Days  
and Hospital Inpatient Days





# Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis

*Clin J Am Soc Nephrol* 11: 633–640, 2016.



# Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis

**Table 2. Multivariate Cox proportional hazards model for survival in 311 patients ages  $\geq 70$  years old (107 patients with conservative management and 204 patients with RRT) using the time of modality choice as the starting point in survival calculation**

Variable	Hazard Ratio	95% Confidence Interval	P Value
Age, yr	1.05	1.01 to 1.08	0.01
<u>Davies comorbidity score (no comorbidity as reference)</u>			<0.001
Intermediate comorbidity	1.89	1.01 to 3.52	
Severe comorbidity	4.11	2.15 to 7.85	
Treatment modality (CM versus RRT; CM as reference)	0.62	0.42 to 0.92	0.02

CM, conservative management.

*Clin J Am Soc Nephrol* 11: 633–640, 2016.



# Conservative Management of End-Stage Renal Disease without Dialysis: A Systematic Review

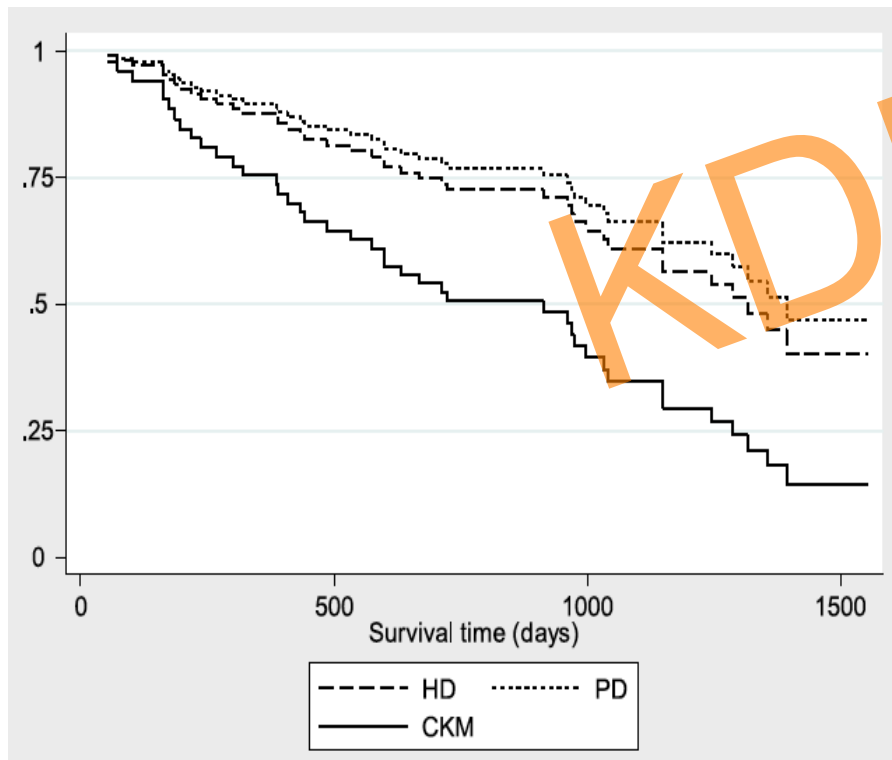
- 6 studies **on symptoms and/or QOL**, mostly cross-sectional surveys
- Median number of symptoms in patients ranged from 6.8 to 17
- The most common symptoms were weakness, lack of energy, poor appetite, pruritus, drowsiness, dyspnea, pain, edema, and difficulty sleeping
- Symptom burden and severity increased in the month prior to death
- 3 studies included a comparison group
  - One of patients with terminal malignancy – mean number of symptoms and impairment in QOL were similar
  - One reported similar symptom burden and QOL between CC and dialysis
  - One reported similar QOL between CC and dialysis

J Pall Care 2012;15:228–235



# Quality of Life and Survival in Patients with Advanced Kidney Failure Managed Conservatively or by Dialysis

- 170 patients attending a predialysis clinic
- Standardized QOL assessment every 3 months for up to 3 years
- At 3 years, 80 had begun HD, 44 PD, 30 CC, and 16 were undecided



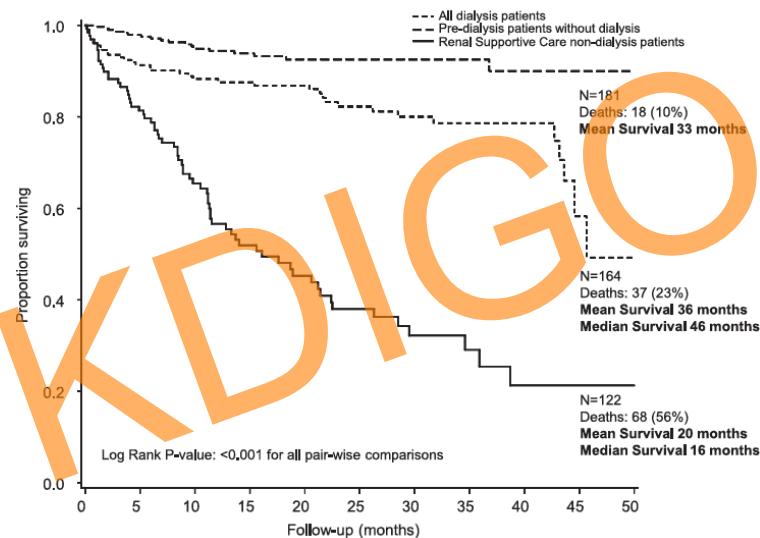
- Patients on CC were older, more highly comorbid with poorer physical health and more anxiety than dialysis patients
- Patients on CC **maintained QOL**, whereas life satisfaction ↓↓↓ significantly after dialysis initiation in the dialysis group
- Mental health, depression and life satisfaction scores were ~ in the two groups at the start of the study

*Clin J Am Soc Nephrol* 7: 2002–2009

KDIGO Controversies Conference on Advanced CKD | December 2-5, 2016 | Barcelona, Spain

# CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life

- 273 patients predialysis who had usual nephrology care and 122 patients on the CC pathway



- With the renal supportive care clinic input, 57% of the patients in the CC group had **stable or improved symptoms** over 12 months, and 58% had **stable or improved QOL**

*Clin J Am Soc Nephrol* 10: 260–268, 2015



# Methodological Issues

- CC population is heterogeneous (older, more comorbidities, reason for decision not to dialyze)
- Varying starting points from which survival was measured
- Likely changes in referral and dialysis practices over time
- Not generalizable to nursing home residents
- For symptom burden and QOL
  - Small group of patients
  - Analyses were not stratified by age and comorbid conditions
  - No head-to-head comparisons for symptom burden and QOL

# Supportive Care: Economic Considerations in Advanced Kidney Disease

## RESOURCES

- Remuneration for screening and management of patient-reported outcomes
- Specialist palliative care services
- Provision of hospice beds for patients with CKD
- New medications for symptom management
- Potential redirection of resources away from dialysis interventions

## EVIDENCE

- Only **2 published economic evaluations** that compare the cost and benefits of dialysis versus non-dialytic care
- Both conclude that dialysis would not be considered cost effective compared with no dialysis at current willingness to pay thresholds
- Neither of them address issues of kidney supportive care appropriately

*Clin J Am Soc Nephrol* ■: ●●●–●●●, 2016



# Supportive Care: Economic Considerations in Advanced Kidney Disease

## CONCLUSIONS

- **Limited data** exist on the cost, the benefits and the cost-effectiveness of kidney supportive care
- There is no consensus on the **optimal method(s)** for economic evaluation of kidney supportive care
- Traditional evaluative **frameworks and outcomes** (e.g., QALYs) should be challenged because they may not capture the true value of comprehensive CC
- Kidney supportive care has the **potential** for both improved outcomes and reduced costs from not using unwanted, resource-intensive care

*Clin J Am Soc Nephrol* ■: ●●●–●●●, 2016



Controversies Conference on Advanced CKD | December 2-5, 2016 | Barcelona, Spain



# Prognostic Tools

- Neither a clinician nor a prognostic score can predict with absolute certainty how a patient will do or how long he will live
- Prognostic tools, however, may improve accuracy of prognostic estimates
  - Identification of high-risk patients
  - Facilitate nephrologist's recommendation for dialysis versus conservative care

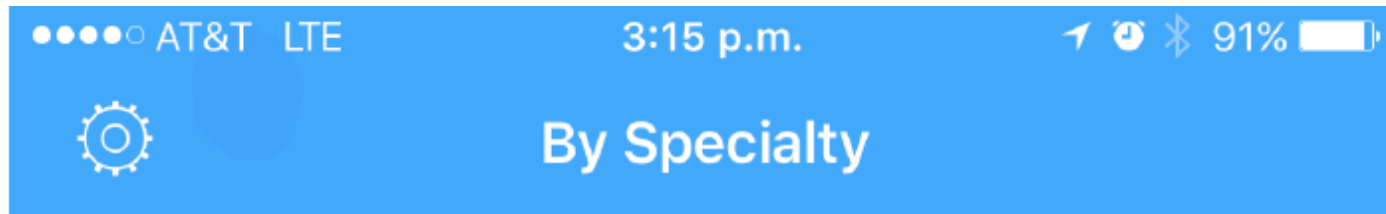
*Clin J Am Soc Nephrol* ■: ●●●–●●●, 2016



# Prognostic Tools

Outcome	Tools	Population	c Statistic
<b>3-mo Survival after dialysis start</b>	• USRDS	• 69,441 incident pts >67 years	0.68 – 0.71
	• French REIN registry	• 28,496 incident pts >75 years	0.75
	• Catalan renal registry	• 1365 incident pts with DM	0.75
<b>6-mo Survival after dialysis start</b>	• French REIN registry	• 4142 incident pts >75 years	0.70
<b>6-mo Survival on HD</b>	• New England HD clinics	• 1026 pts on chronic HD	0.80

# QxMD



## ▼ Hemodialysis

3-Month Mortality in Incident Elderly ESRD Patients >

Estimate the risk of early death (at 3 months) in elderly patients starting dialysis.

6-Month Mortality on HD >

Estimate 6 month mortality on dialysis



# QxMD

AT&T LTE 3:16 p.m. 91%

< 3-Month Mortality in Incide... ☆ ⓘ

Gender? Male >

Age? 75-84 >

Congestive Heart Failure? None >

Peripheral Vascular Disease? Grade I or II >

Dysrhythmia? No >

Active Cancer? No >

Severe Behavioral Disorder? No >

Mobility? Walks without help >

Serum Albumin?  $\geq 3.5$  g/dL >

AT&T LTE 3:17 p.m. 91%

< 3-Month Mortality in Incide... ☆ ⓘ

Serum Albumin?  $\geq 3.5$  g/dL >

Results

Score
1

Estimated Risk of Death at 3 months After Dialysis Start

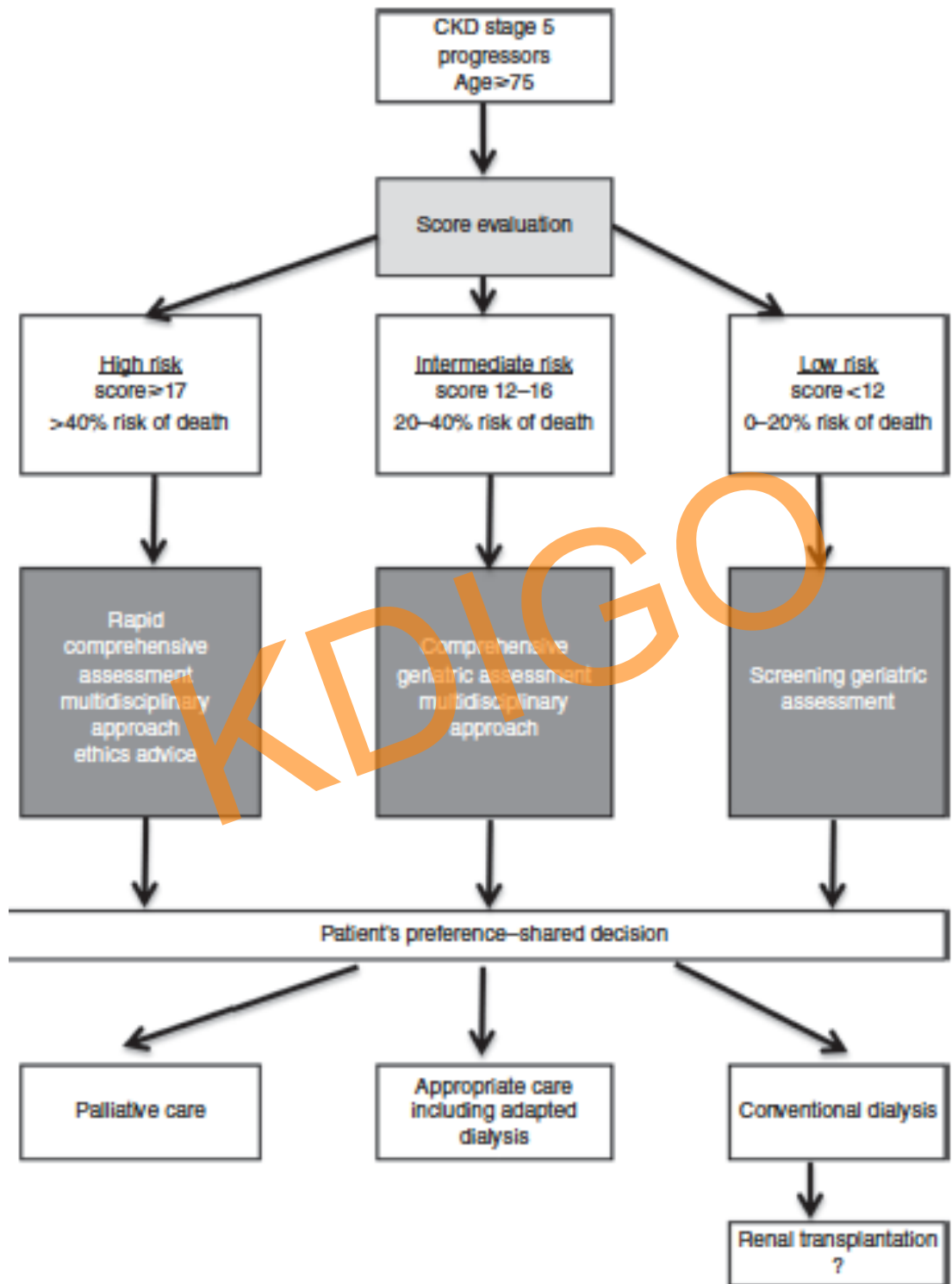
**<20% Risk of Early Death**

Suggested Approach

**Screening geriatric assessment by the health professionals of the dialysis unit**

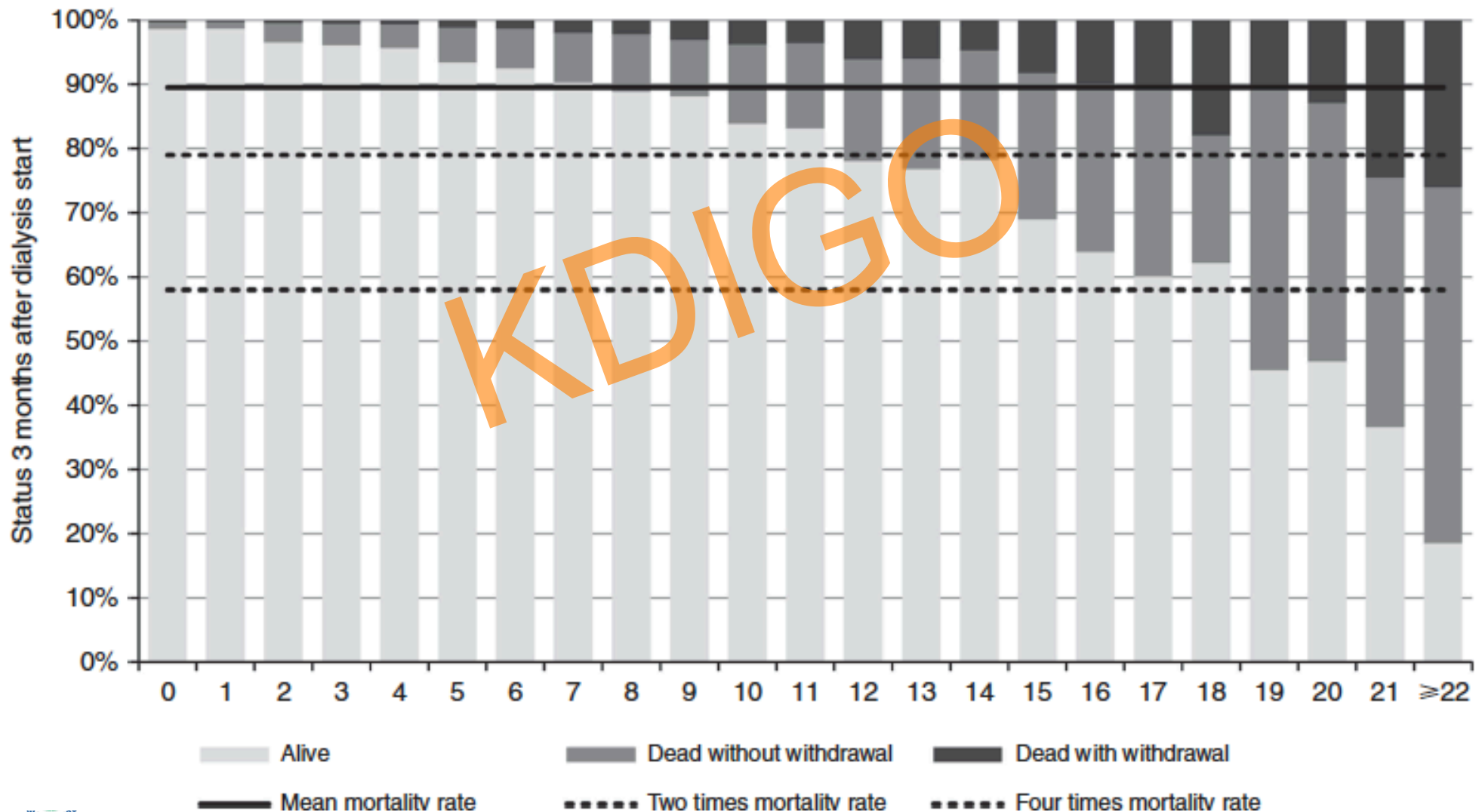
KDIGO





# Development of a risk stratification algorithm to improve patient-centered care and decision making for incident elderly patients with end-stage renal disease

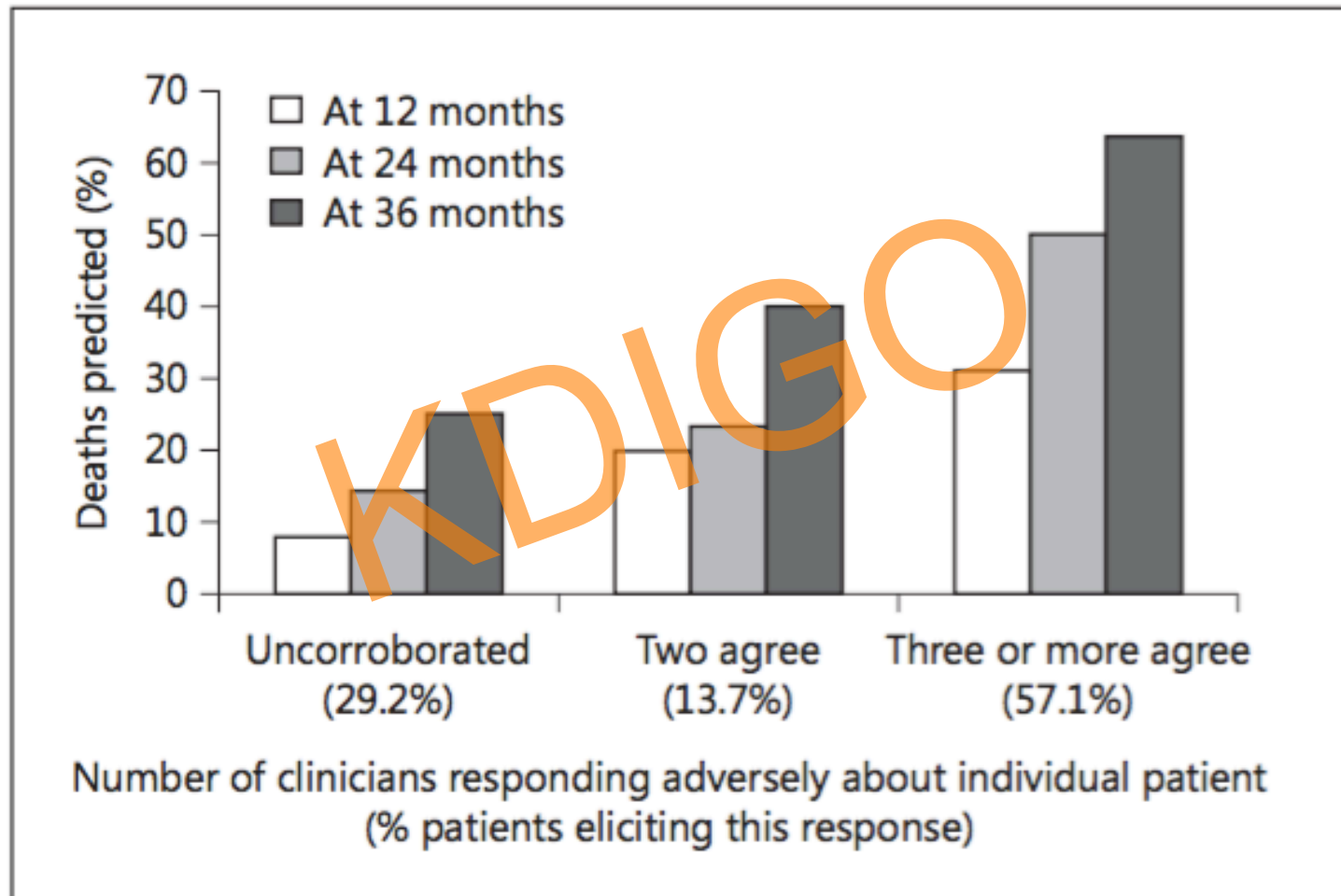
*Kidney International* (2015) **88**, 1178–1186



# Limitations of Current Prognostic Tools

- Only a few of them focus on short-term survival (<6 months)
- Other factors, such as self-rated health question, perceived treatment control, patient's illness perception, Karnofsky performance score, or frailty, are related to survival, but their prognostic value for short-term mortality (<6 months) has not yet been evaluated
- Clinical intuition may add value

# “Surprise Question”



Nephron Clin Pract 2013;123:185–193.



# Use of Prognostic Tools in Practice

- **Survey of Canadian nephrologists**
  - **80%** of the respondents were **not satisfied** with their current ability to predict clinical trajectories
  - Strong support for **further development** and uptake of validated prognostic tools to enhance appropriate care that is aligned with patients' priorities and illness trajectory

Can J Kidney Health Dis 2: 53, 2015

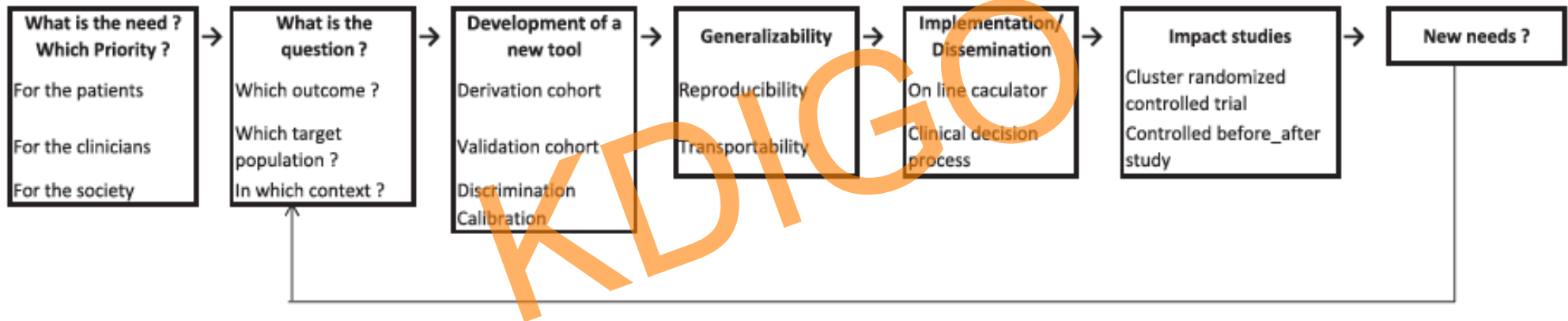


# Need for New Tools

- Assess outcomes other than survival that are **relevant to patients and families**
  - HRQOL
  - Physical function
  - Hospitalization
  - Place of death
- Potential new **predictors**
  - Sentinel events (changes in hospitalizations, HRQOL, body composition, clinical data)
  - Biomarkers (systemic inflammation)
  - Patient's health reports (frailty, gait speed, appetite, fatigue)
  - Other variables from scores developed for other populations (PRO)



# Framework for Development of a New Tool



KDIGO has recommended that **methods of communicating prognosis** and integrating the biomedical facts of prognosis with the emotional, social, and spiritual realities of the patient should be developed and evaluated along with research into methods of how to communicate the uncertainty of predicting outcomes and individual patient trajectories.

# Recommendations - Education

- Supportive care should be recognized as a **core competency** for practicing nephrologists (CME) and trainees (nephrology curriculum)
- Enhance **cross-cultural** competency and **communication** skills
- Assess **education and skill needs** across various settings and disciplines
  - Provision of supportive and end-of-life care by generalists and community providers as a component of usual care

Kidney Int 2015;88:447–459  
Clin J Am Soc Nephrol 11: 1902–1908, 2016



# Recommendations – Research & Advocacy

- Develop international consensus on the **terminology and definitions** of CC to promote shared understanding and consistent clinical practice, research, and policy
- Determine the **illness trajectory** for those managed with CC and how this compares with those managed with dialysis
- Analyze **outcomes** of CC other than survival, including HRQL, symptoms, functional status, illness and care experiences including family experiences, hospitalizations, and quality of dying
- Develop cost-effective **models** for the provision of CC across diverse health systems, cultures, and available resources
- Define quality of supportive care **metrics** and optimal methods of **integration into payment and accreditation/regulatory models**

Kidney Int 2015;88:447–459

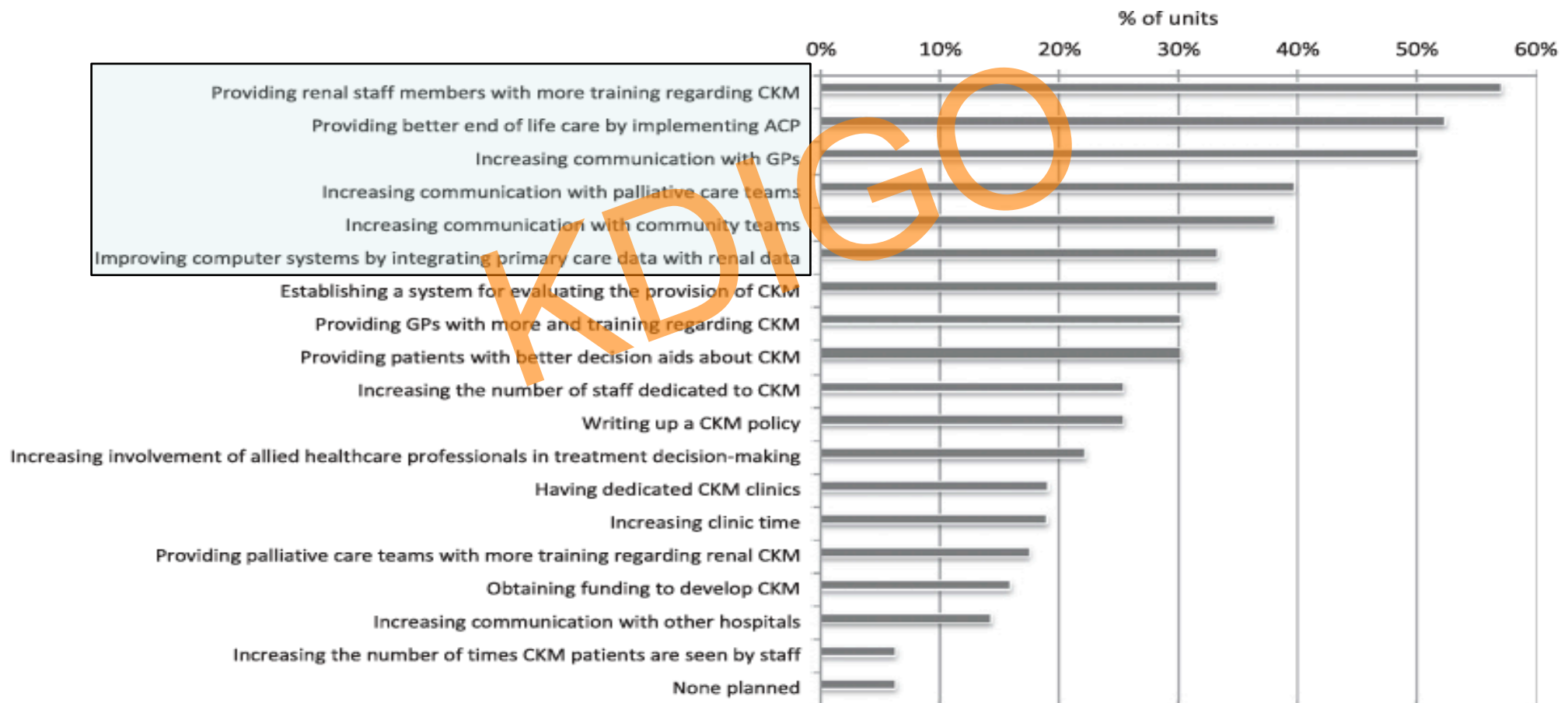
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# Conservative Care for ESRD in the United Kingdom: A National Survey

*Clin J Am Soc Nephrol* 10: 120–126, 2015

What, if any, of the following changes are planned in your unit regarding the provision of CC?



# Examples of Strategies in HIC

**Ontario Renal Plan II (2015-2019)**  
Prioritizes palliative and end of life care among renal patients.



- 1 Educate providers, patients and families** about the benefits of a palliative approach to care for people living with CKD to strengthen service capacity and build awareness.
- 2 Strengthen system accountability** by establishing local clinical champions within nephrology in the Ontario Renal Network Regional Renal Programs to support a palliative approach to care.
- 3 Support shared understanding** of palliative care needs for CKD patients through common terminology among providers across care settings to facilitate clear communication and terminology that is recognizable to patients and families.
- 4 Introduce conversations** about advance care planning and goals of care early. Create accountability to support and review these goals with patients regularly through their care journey.
- 5 Adopt a standard approach** to identify who may benefit from a palliative approach to care, to assess symptoms and to manage care.
- 6 Develop key performance indicators** to measure progress in the next three years.

# Examples of Strategies in LMIC



Servicio de Salud Talcahuano  
Ministerio de Salud



UNIDAD DE CUIDADO RENAL  
AVANZADO (UCRA)

Cuidados continuos en la Enfermedad Renal Crónica:  
tratamiento conservador y paliativo



Leading  
European  
Nephrology

