

Patient involvement in academic research: the value of early chronic kidney disease (CKD) intervention

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The European Patient
Research Network

LSE HEALTH

- Comprised of four affiliated research units:
 - **Medical Technology Research Group (MTRG)**
 - The Centre for the Study of Incentives in Health (CSI)
 - Healthcare Information Systems Group
 - Risk Research Unit
- Responsible for several, complementary streams of research:
 - Health policy
 - Health economics
 - Demography and health
 - The European Observatory on Health Systems and Policies
- Boasts research awards totaling £48 million and publication of 1600 peer-reviewed journal articles, books, and reports since 2004.

MEDICAL TECHNOLOGY RESEARCH GROUP

Three core activities that operate in parallel:

(I) Conduct of basic and policy-relevant research

- **Patient-centred research**
- Generic medicines
- Disease-specific: rare diseases, diabetes, cancer
- Value-based pricing for pharmaceuticals
- Performance measurement in health/drug policy
- Experimental health economics
- Economics of medical technologies
- Access to medicines and medical technologies in low- and middle-income countries

MEDICAL TECHNOLOGY RESEARCH GROUP

(2) Formation of research networks and platforms

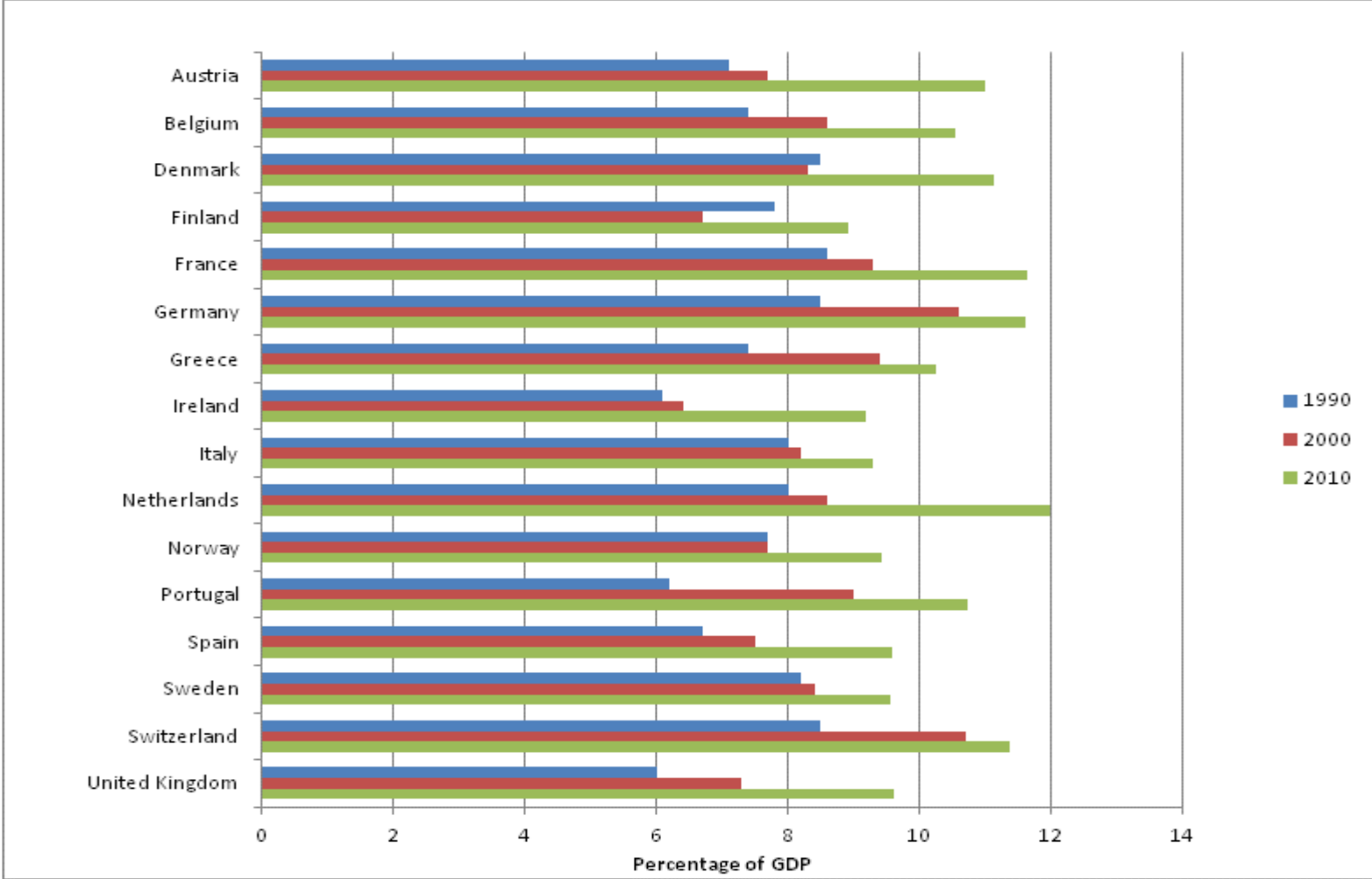
- **The Patient Research Network (PRN)**
- EMINet
- BURQOL-RD
- EPIRARE
- Advance HTA
- RARE-Bestpractices
- Diabetes network in emerging countries
- European Observatory on Health Systems and Policies

(3) Development of training resources

- Health Technology Assessment (HTA) Courses
- Health Negotiations
- HTA Masterclass



HEALTH CARE EXPENDITURE (% GDP) IN THE EU



VALUE OF EARLY DISEASE INTERVENTION

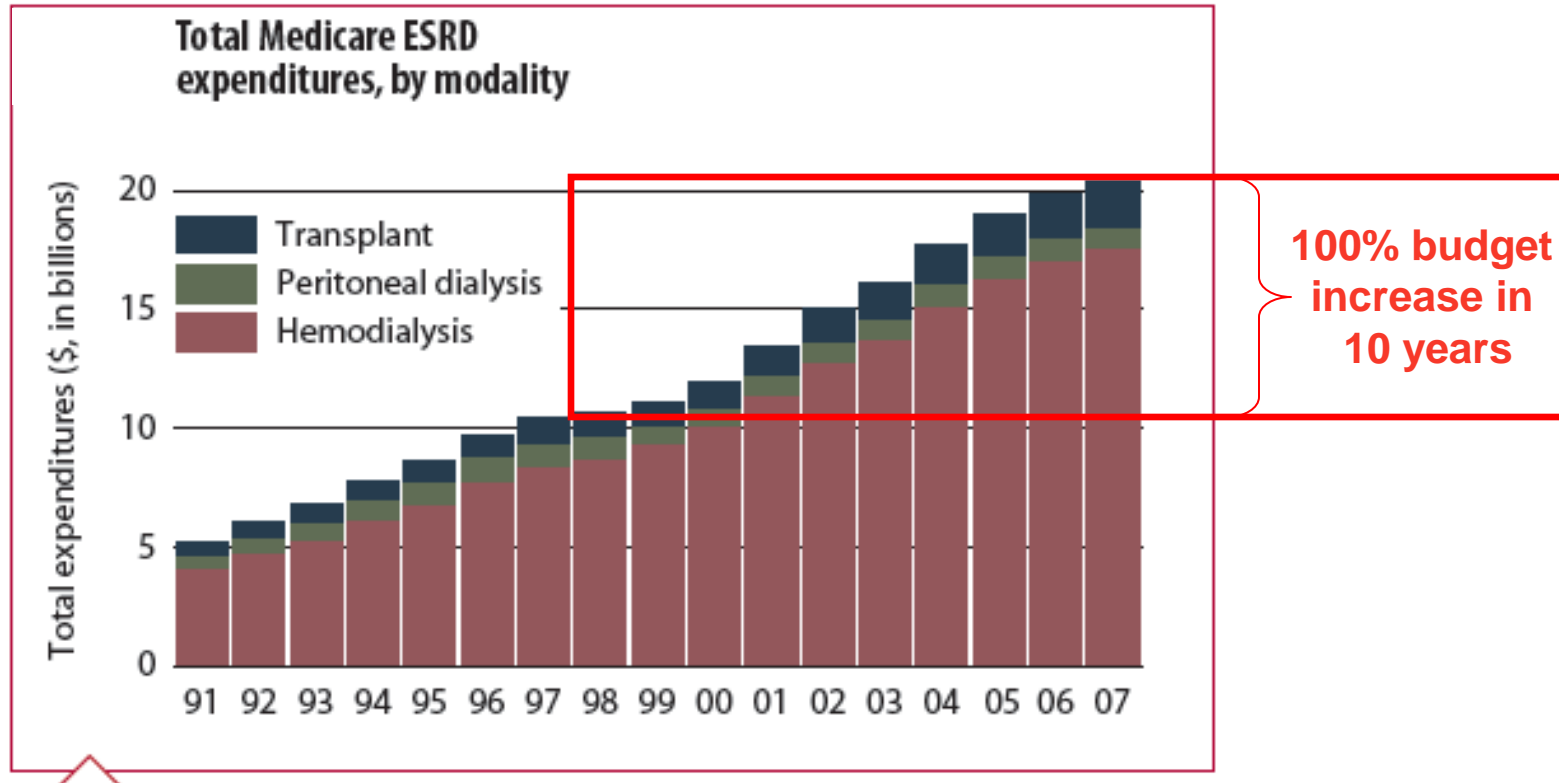
- Early disease intervention usually improves health outcomes and minimises long-term health care expenditure.
- The treatment of chronic conditions is especially resource-intensive, and early intervention can relieve economic pressure on health care systems.

CASE STUDY: CHRONIC KIDNEY DISEASE (CKD)

- Chronic kidney disease (CKD) refers to a heterogeneous group of disorders that cause the deterioration of kidney structure and function.
- CKD can lead to end-stage renal disease (ESRD) which requires dialysis or kidney transplant.
- In most developed countries, ESRD patients represent around 0.1% of the total population, but account for approximately 5% of national health care budgets in OECD countries.

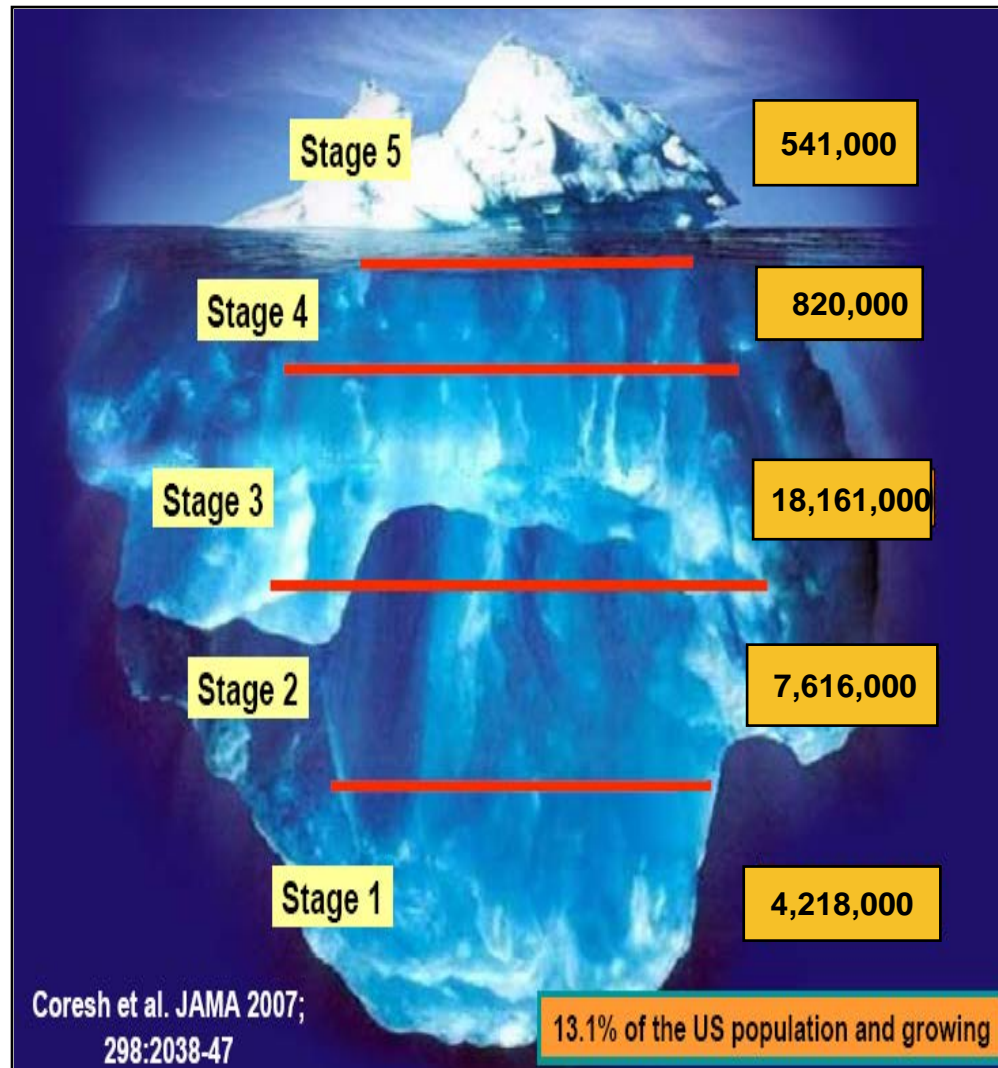
Stage	Description	Estimated glomerular filtration rate (eGFR) (ml/min/1.73 m ²)
1	Kidney damage and normal or ↑ eGFR	≥ 90
2	Kidney damage and Mild ↓ eGFR	60-89
3	Moderate ↓ eGFR	30-59
4	Severe ↓ eGFR	15-29
5	Kidney failure usually need dialysis	<15

RISING GLOBAL COSTS OF ESRD



Estimated global health care expenditure on ESRD: >US\$1 trillion

DIALYSIS REPRESENTS THE TIP OF THE ICEBERG



EVIDENCE ON UPSTREAM CKD TREATMENT (I)

- Early nephrologist referral
 - Although nephrologist involvement is needed in advanced CKD cases, the available data suggest that the early stages can likely be adequately addressed by primary care physicians.
- Screening strategies
 - Targeted screening of high-risk groups (i.e. diabetic and hypertensive patients) was a cost-effective strategy in most studies.
 - Screening was increasingly favourable under all conditions as screening started at a later age (e.g. individuals ≥ 60 years) or screening frequency decreased (e.g. every ten years).

EVIDENCE ON UPSTREAM CKD TREATMENT (II)

- Pharmacologic intervention
 - The data suggest dominant or highly cost-effective treatment strategies (e.g. angiotensin-converting enzyme [ACE] inhibitors, angiotensin receptor blockers [ARBs], statins, etc).
 - Early initiation of treatment during stages 1-3 is likely to optimise health outcomes and minimise medical expenditure.
- Dialysis delay
 - US studies have estimated that slowing the rate of CKD progression by 10-30% in the affected population would translate into annual cost savings of US\$1.9-6.6 billion.

HEALTH POLICY IMPERATIVES

- The available evidence suggests a positive socioeconomic impact and improved health outcomes from early diagnosis, treatment, and management of CKD.
- Requires an integrated care model that also targets common comorbidities (e.g. hypertension and diabetes).
 - Improving health care outcomes requires a unified patient care strategy across key stakeholders to incentivise a long-term care perspective.
- This holds true for CKD, a particularly complex disease involving a multitude of providers over a patient's life time, but applies to all chronic diseases in general.

CONCLUSIONS AND RESEARCH OPPORTUNITIES

- The European Patient Research Network (EPRN) aims to provide a continued and sustainable link between the academic, policy-making and patient communities.
- It is important to equip patient groups with the knowledge and evidence to participate actively in health care reform and resource allocation debates.
- CKD can serve as a comparator group for other evaluations of socioeconomic benefits of early disease intervention (e.g. neurological conditions, such as Parkinson's and Alzheimer's disease).

TRAINING RESOURCES: CAPACITY BUILDING

“It is important to equip patient groups with the knowledge and evidence to participate actively in health care reform and resource allocation debates”...



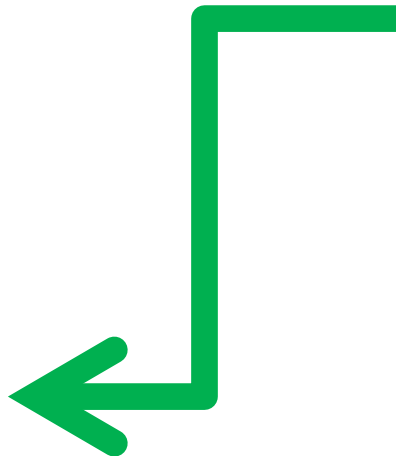
“It is important for patient groups to equip researchers with the knowledge they need to conduct patient-relevant research”...

TRAINING RESOURCES: CAPACITY BUILDING

HEALTH TECHNOLOGY ASSESSMENT



PHARMACEUTICAL PRICING, ACCESS AND REIMBURSEMENT



- *Rate of Return Regulations*
- *Price Referencing and Tendering*
- *Patient Access Schemes*
- *Generic Pharmaceutical Policy*
- *Risk Sharing*
- *Adherence to Medicines*
- *Value Based Pricing*
- *Prescribing Policies and Incentives*

TRAINING RESOURCES: CAPACITY BUILDING

- FREE Workshop for Patient Advocates on Pharmaceutical Pricing, Access and Reimbursement
- An initiative of the European Federation of Neurological Associations [EFNA], run by the London School of Economics
- EFNA covers two nights accommodation and travel
- Next Courses: June 24-25 (registration closed) and September 16-17
- By attending this course, participants will obtain insights on:
 - (a) how pharmaceuticals fit within the overall health care system
 - (b) how different countries in Europe and beyond pay for pharmaceuticals
 - (c) what are the most salient regulations addressing coverage/access and how these affect patient access
 - (d) how stakeholders - including patients - participate in the decision-making process.
- To register or for more information email executivedirector@efna.net



Empowering Patient Neurology Groups

For more: www.efna.net