

A healthcare professional in colorful scrubs is showing a tablet to a patient. The background is a bright, clinical setting. The text is overlaid on the image.

PaRIS

Patient-Reported Indicators Survey initiative
Measuring what matters to people

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Health systems are under pressure

1 Rising costs and too much waste

2 Care becomes increasingly complex (multi morbidity)

3 We don't really know what health systems deliver to people



This leads to demand for putting people more at the centre of our health systems

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“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”

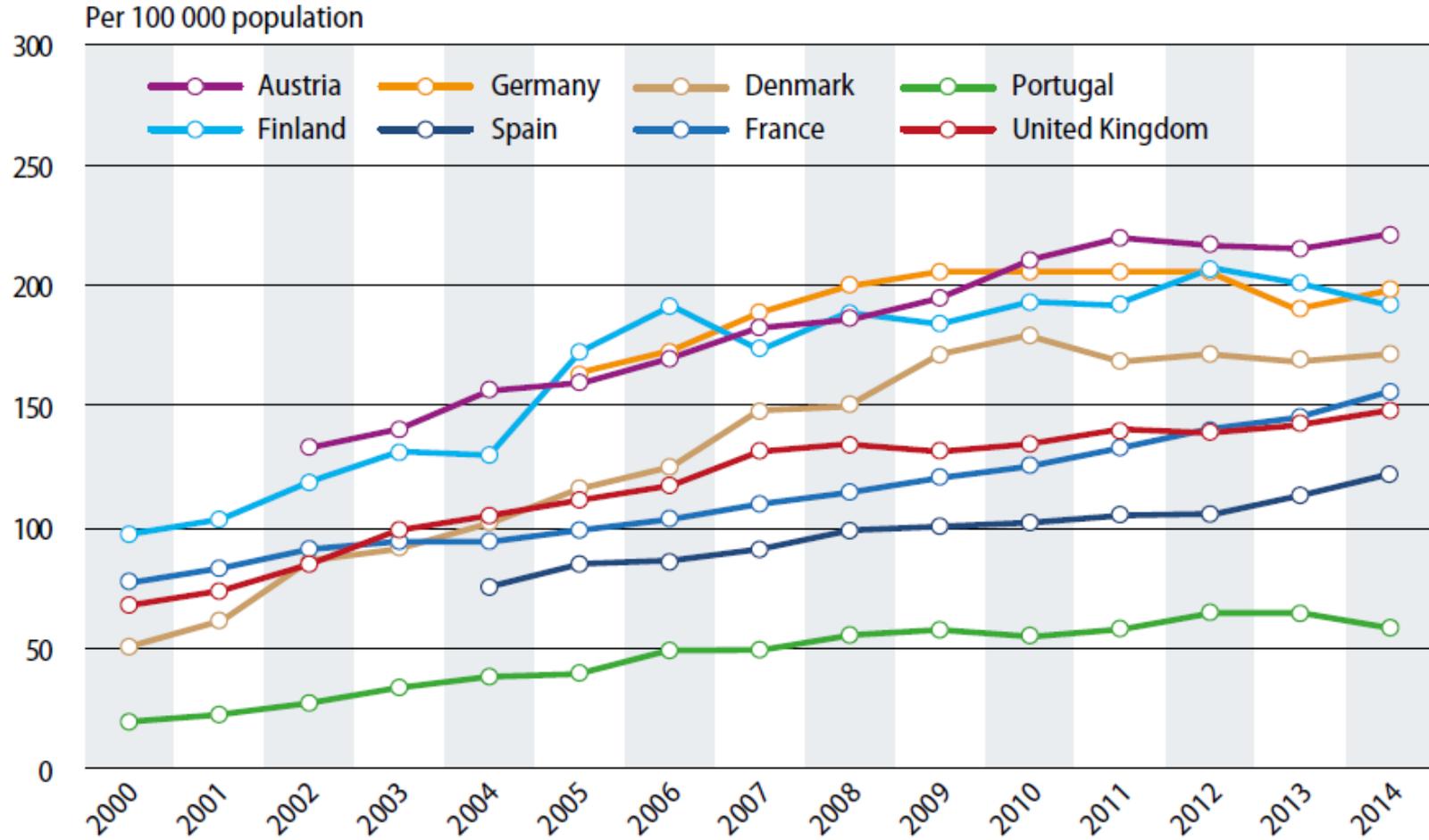


We have substantial information gaps to address those pressures

- Health care seeks to improve people's **well-being** and their ability to realise goals. Yet health systems **know very little** about whether or not they are successful in this.
- We have good measures of inputs & outputs. But patients' ability to live **normal, functioning lives** is **rarely captured** in a robust, standardised way.

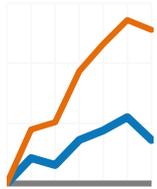


Large variation in volumes: are we delivering too little care? Too much?



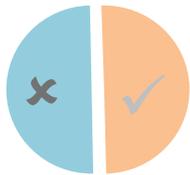


To achieve better value we need better information on



To what extent are people in **pain** after **hip surgery**?

What is the **health-related quality of life** for people receiving **cancer** treatment?



Can people **live independently** after a **stroke**?

How well can people with a **mental health** condition **live independently** after discharge?



What was a person's **experience of their care**?



WHAT *PARIS* WILL DO



Priority areas for specific conditions



Hip and Knee Replacement

- Working Group been meeting since Nov 2017
 - R&D work led by CIHI in Canada
 - Currently working on cross walks across existing tools, first data expected in 2019
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Breast Cancer

- Working Group been meeting since Jan 2018
 - R&D work led by OECD.
 - Currently focussing on pilot data collection
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Mental Health

- Working Group been meeting since July 2018
- R&D work led by Denmark
- Currently scoping issues for ongoing development
- Establishing a patient and carer advisory group



New international survey of patients with chronic conditions – under development

- Focuses on **people aged 45+ with (multiple) chronic conditions**
- Covers both **outcomes and experiences**
- **Ambulatory/ primary care** (best possible option to reach suitable patients)
- Indicators relevant for policy makers, patients and health care providers
- Overall health status; physical functioning, pain; social functioning and participation
- Plan to integrate digital technology to minimise collection cost
- Alignment with national initiatives
- Survey design and the practices of data processors fully protect the privacy of survey participants
- Patient-level data that can be linked to higher levels



What it means for EU countries

- Phase 1 of the chronic patients survey (development of instrument and sampling design per country).
- Working groups in different stages
- **All EC countries (including non-OECD members) are encouraged to join the PaRIS initiative**
- EC is an important partner who contributes substantially to PaRIS
- At 7 November, the first meeting of the working Party for PaRIS took place. The meeting was attended by 25 countries.



EU-countries already involved

- Belgium, Czech Republic, Denmark, Estonia, France, Greece, Italy, Latvia, Lithuania, Luxembourg, Netherlands, Slovak Republic, Slovenia, Spain, United Kingdom.
- Non-EU: Australia, Chile, Iceland, Israel, Japan, Korea, Mexico, Norway, Switzerland, United States



Thank you and keep in touch!

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