Parkinson's Disease Patient Journey

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Background

Parkinson's Disease (PD) is a chronic progressive disorder of the central nervous system. Approximately 1.25 million people (mainly elderly) are affected in Europe and the figure is expected to double within the next twenty years. The diagnosis is mainly based on the following cardinal symptoms: rigidity, tremor, bradykinesia and impaired postural reflexes. Whereas the symptoms can easily be controlled in the first years, PD may lead to a considerable loss of quality of life, to care dependency and disability in the advanced stage. The financial burden for both, the patient (and his family) as well as the society, is enormous. Currently, about 12% of the European budget for neurological diseases is spent for PD which is the second most common neuronal disease after Alzheimer's disease.

Methods

A multi-disciplinary team with patient representatives, clinical experts, health economic experts and industry partners worked together from May 2016 until June 2017 to evaluate diagnosis and treatment gaps of PD in Europe to identify best practices and solutions for better PD care models in Europe to prepare recommendations how to implement proposed solutions. A detailed patient journey matrix has been prepared to identify the current gaps of PD care – starting from prevention, screening/prodrom, early intervention, disease management, disability and rehabilitation, until end-stage management and palliative care. The most relevant issues have been identified by the team for further evaluation. Literature and research reports (like MyPD Journey research reports from EPDA2 or what matters most? From Parkinson´s UK2) have been used to identify best practices in Europe and to prepare recommendations for better PD care (Lit from NL and Israel). A sub-team has investigated the economic and quality of life impact of the identified treatment gaps on the patients and the society (see VoT PD poster economic evaluation).

The Care pathway: Treatment Gaps and Unmet Needs

1. DELAYED OR INADEQUATE DIAGNOSIS

Although 50% of patients are diagnosed by a PD specialist, there is a high risk of a delayed or inadequate diagnosis.
The range of PD symptoms is diverse and most symptoms are common to other diseases.

2. NO ADEQUATE TREATMENT

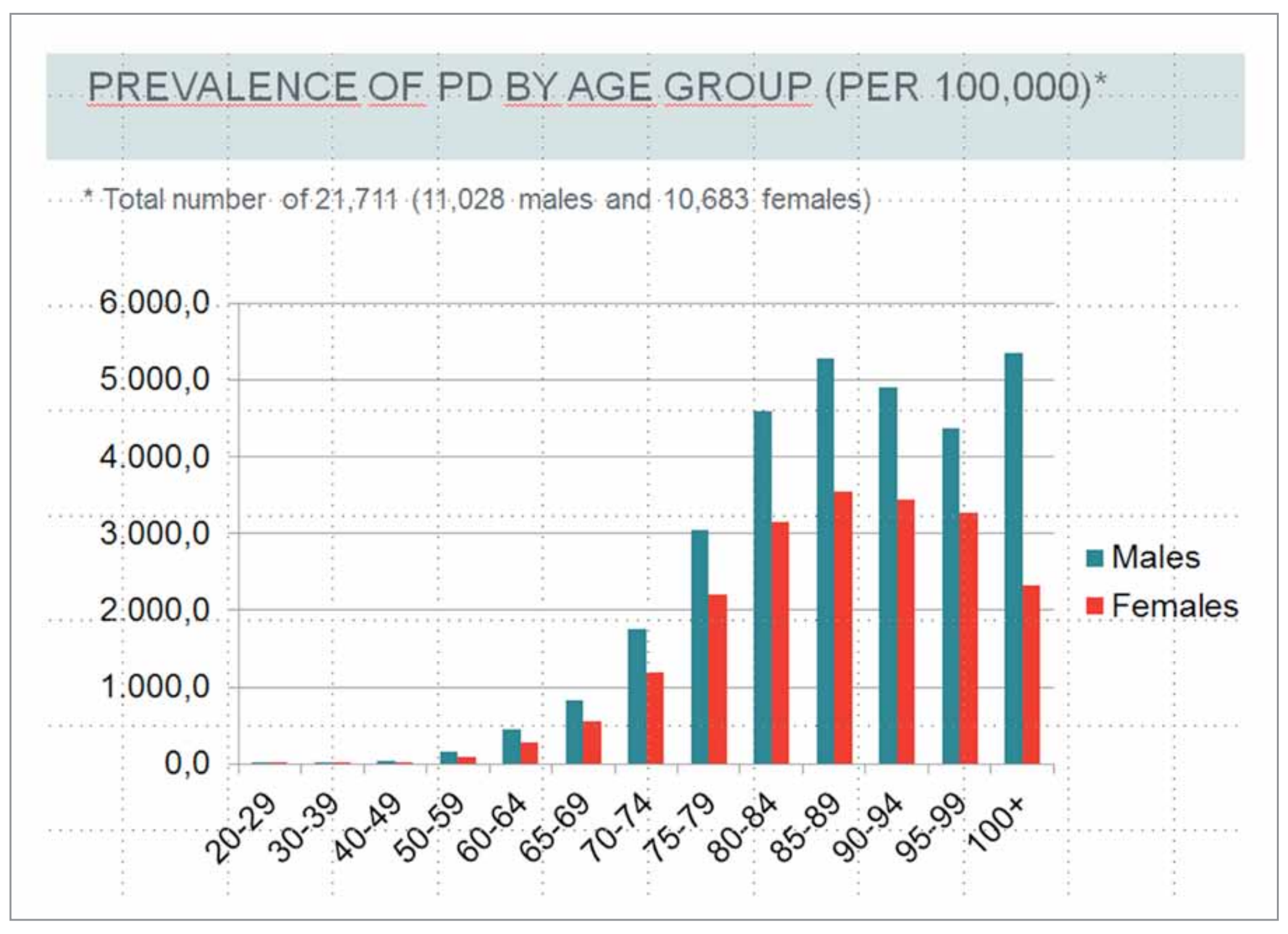
Adequate treatment of PD gets more and more difficult with the propression of the disease. Many aspects like age of a patient, change with individual symptoms, existing co-morbidities, potential of side effects of treatment have to be taken into consideration and require the knowledge of PD specialists. Currently, not every patient in Europe has access to PD specialists and new PD therapies (surgical techniques, pump therapies).

3. NON-ADHERENCE TO TREATMENT

PD patients frequently show poor adherence to prescribed therapies than they actually do. Better treatment adherence is important for patient's well-being and has a significant cost impact on the health care system.

Recommendations

1. Better information and **active involvement of patients and caregivers** will help to identify the best possible treatment and will result in a better treatment-adherence.
2. **Improved communication and coordination** processes will help to establish integrated and multi-disciplinary care systems. Countries and regions that are leading in this respect might share their knowledge and their experiences.
3. Each patient should have **access to the best possible treatment and therapy** at each stage of the disease.
4. The **public needs to be better informed** about the complexity of PD and patient needs. Patients (especially the younger ones!) should not need to worry about stigmatization.
5. **More investment in research** including basic science, patient-oriented research and development of new treatment solutions is required. Currently, research allocations to brain disorders do not match with the socioeconomic impact of the disease as proposed by the European institutions.



What matters to Patients and Caregivers?

Diagnosis

"I was diagnosed 2 ½years ago, although I had it for five years. I went to 14 appointments with different neurologists and they all failed to recognise I had the disease […]."

(Patient, Italy)

Treatment

"They thought he may have a brain tumour. I have to say we were very unlucky with our neurologist. He sent us the diagnosis per fax…can you imagine? He did not even bother to call him in for a conversation."

(Carer, Germany)

Acceptance

"He was sent home with a prescription and the Consultant told him they would make him feel better but we were not told about the side effects. First week was grand as it was a low dose, the second week was a nightmare cause of his blood pressure… One night I thought he was going to die in the bed on me. I can honestly say, in those initial years, he was over medicated."

(Carer, Ireland)

Coping

"One thing which is difficult with Parkinson's is that it is so unpredictable. It varies so much from day to day, hour to hour so you just have to take every day as it comes."

(Carer, Ireland)

Conclusions

Decision and policy makers are asked to act soon in order to face the financial and societal burden resulting from an increasing number of patients suffering from PD in Europe. A good balance is needed between cost effectiveness of PD diagnosis & treatment and the well-being of the individuum. Due to the high complexity of the disease, better knowledge and well-coordinated care models are needed as already available in some countries in Europe. Support of politicians is requested to broadly implement available solutions and known best practices in all European member states.

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A digital version of the poster including references and other supporting documents is available here:
http://www.braincouncil.eu/activities/projects/the-value-of-treatment/PD

The economic benefit of a timely, adequate, and adherent approach to Parkinson’s Disease treatment

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Background

Parkinson’s disease (PD) is a chronic progressive neurodegenerative disease affecting approximately 7 million people globally with devastating socioeconomic effects on individuals, their families and society. Total European costs of PD in 2010 alone accounted for €13.9 billion [1]. The global prevalence of PD is increasing over time and it is expected to double within the next 20 years (up to 2% in people over the age of 60 and 6% in people over 80 years [2]). The current investigation goes into more detail on major cost drivers based on the specific needs of the patients identified in the patients’ journey. We have focused on three major topics: Lack of early/timely treatment; Lack of adequate treatment for advanced PD; and Lack of treatment adherence.

Methods

Lack of early/timely treatment. The first economic analysis looked at the short term cost-effectiveness gains attached to treatment start at different stages in the patient journey (graded according to Hoehn and Yahr stages (H&Y) compared with no treatment. With a decision analytic modelling approach, we evaluated the impact of a hypothetical treatment (with fixed gain in effectiveness compared with no treatment as per published data of early PD interventions[3,4]) when given to patients at different health states (Hoehn and Yahr stages, H&Y). Annual cost estimates were reported for the societal perspective ([5] inflated to 2017 figures, Euros). Effectiveness was expressed in terms of Quality Adjusted Life-Years (QALYs) gains. Cost effectiveness was reported in terms of incremental cost effectiveness ratio (ICER). Published economic and QALY data for different H&Y stages [6] were used to create a matrix that enabled to attach annual societal costs [5] to different QALY values (health states; see figure 1). Sensitivity analyses were applied to test the robustness of the model according to variation in the QALY improvements (0.05-0.10-0.15 QALY) and intervention costs (zero up to 6 Euro daily). Two separate EU healthcare systems were considered, including Germany and UK.

Lack of adequate treatment for advanced PD. A second set of analyses evaluated the cost effectiveness of best treatment in advanced PD (deep brain stimulation (DBS) and best medical treatment BMT) compared with current care. The analysis looked at direct costs (2017 figures , Euros) and QALYs comparing a current scenario where only a small proportion of eligible patients receive best treatment (2% on DBS+BMT) vs 88% on BMT vs 10% no treatment, with a target scenario where a larger number of patients receive best treatment (15% on DBS+BMT) vs 85% on BMT only (see figure 2). Published economic evidence representing clinical progression and capturing treatment effect (QALY) and costs using Markov modeling techniques were used to provide long term (5 years) cost and QALY evidence for two different healthcare settings (Germany [7] and UK [8,9], discount rates 3% and 3.5% per annum respectively).

Lack of treatment adherence. A third set of analyses looked at the economic impact of: adherence to treatment (e.g. looking at the change in average patient healthcare costs according to level of adherence); and of a shift towards increased adherence to treatment in the PD patient community. With a decision analytic model (figure 4) we calculated the economic savings (2017 figures, Euros) when moving from status quo (current care) to a target scenario with improved adherence rates. Outcomes for the economic evaluation were healthcare costs (drug costs, A&E, hospitalisations, GP visits, day care and care home stay). A timeframe of 1.5 years was considered. Sensitivity analyses looked at grouping patients according to different definition of adherence (Duration of therapy, DOT, or medication possession ratio, MPR*). Use of resources data were extracted from previous publications [10-12]. Unit costs for Germany ad UK were sourced elsewhere ([13-16] and [17-18]). The perspective adopted was for the public health insurance (Germany) and NHS (UK).

**Duration of therapy (DOT) - it assesses the duration of time, or persistence that a patient is treated with APDs. DOT was measured as the number of days between the first and last filled prescription of all PDs and the days’ supply of the last fill, date of death, or the end of 19 months or whichever came first. Medication possession ratio (MPR) - it assesses how regularly patients take APDs while in their possession. Calculated as the total days’ supply from all APD classes (numerator) divided by the aggregate DOT of all drug classes (denominator).*

Results

Lack of early/timely treatment. A short term modelling (one year time frame) suggests that the hypothetical PD treatment intervention is cost-effective regardless of the initial health state of the patient receiving the treatment(Germany cost savings between -1000 and -5400 Euros with 0.10 QALY gain; UK cost saving of -1800 and -7600 with 0.10 QALY gains, see Figure 2). When the treatment enables the patient to improve to a less severe H&Y stage (e.g. transitions from stage 2 to 1, from stage 3 to 2 or from stages 4/5 to 3; figure 2) it was found not only a more effective but also less costly option (compared to no treatment). The cost savings increased with the severity of the disease (e.g. the transition from stage 4/5 to 3) was more cost saving than from stage 3 to 2; e.g. -5400 Euros vs. -1030 Euros as economic impact of 0.10 QALY gain in Germany; -7600 Euros vs. -6000 Euros as economic impact of 0.10 QALY gain in UK). Sensitivity analyses showed that the treatment remain cost–effective within the NICE thresholds (or cost-saving when shifting between H&Y stages) even the worst scenario (with the most costly intervention option). When doubling or tripling the treatment effectiveness from 0.05 to 0.10 or 0.05 to 0.15 the window of opportunity to move to a less severe H&Y stage increased proportionally. The findings were consistent across healthcare systems. If we extrapolate the results to model the economic impact of early/timely treatment on a longer period (5 years or more) we can anticipate that such practices would enable to decrease the related societal and health care costs across healthcare systems.

Lack of adequate treatment for advanced PD. Results showed that making available the adequate treatment to more patients is cost effective (ICER euros 15,000 to 32,600 across country settings), where an increase in direct costs is accompanied by a gain in QALYs (compared with current care; see table 1).

Lack of treatment adherence. Results showed that low level of adherence would correspond to an increase in annual patient costs (increase of 20-40% in Germany and 80-300% in UK depending on the definition of adherence used; see figure 5). More use of hospital and residential/nursing care home services were the main drivers of such increases. Meeting the target adherence to treatment rates would generate a cost saving of 239,000-576,000 euros (Germany) and 917,000-2,980,000 euros (UK) every 1000 patients treated adequately.

Conclusions

The economic analyses confirmed that timely, adequate, and adherent approach to Parkinson’s disease treatment are paramount to: reducing the risk of disease progression; limiting the effects of PD on quality of life; and tackling the economic impact on service providers across healthcare systems.

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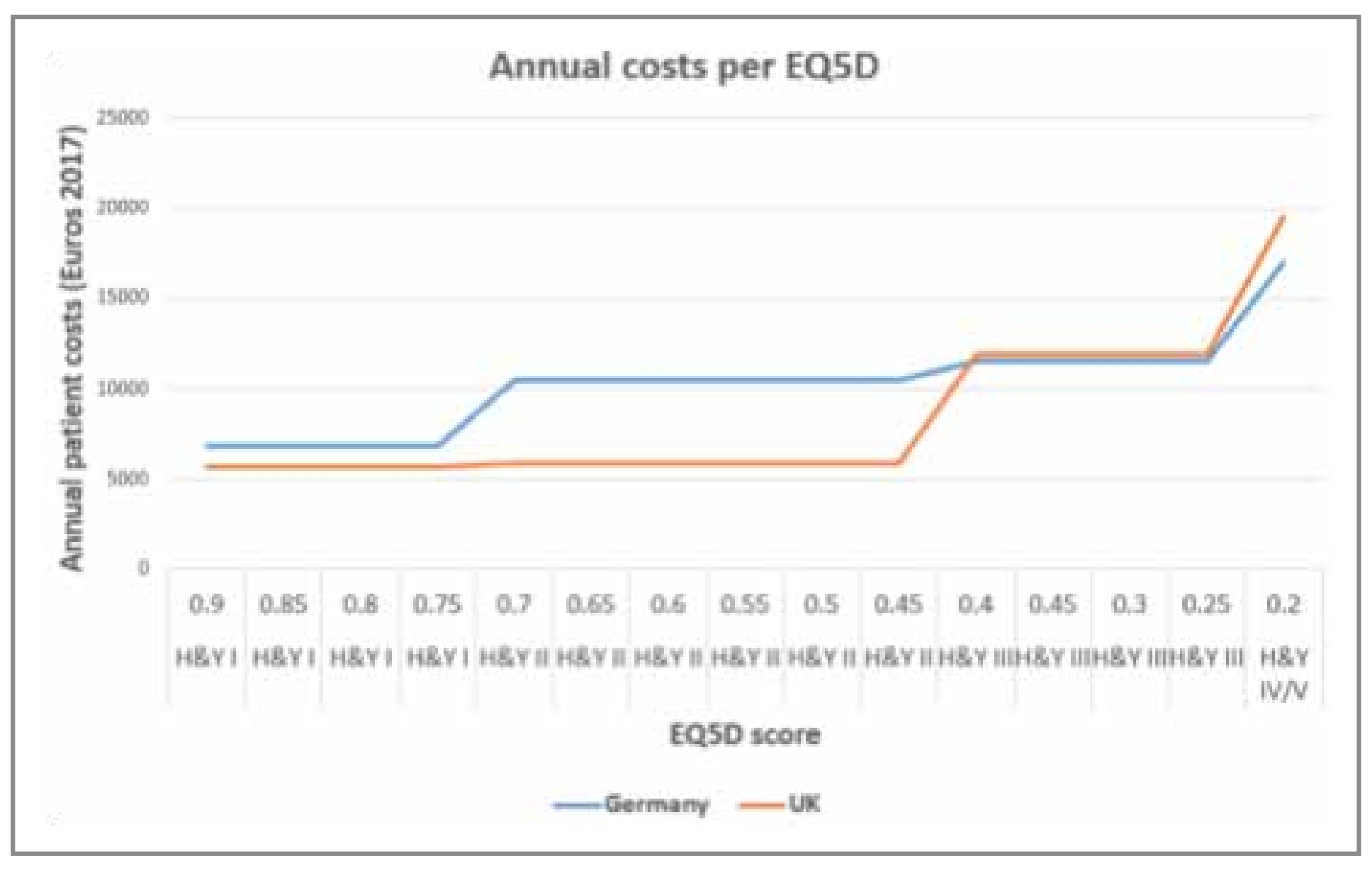


Figure 1: **Lack of early/timely treatment.** Annual costs according to EQ5D score/severity of the disease

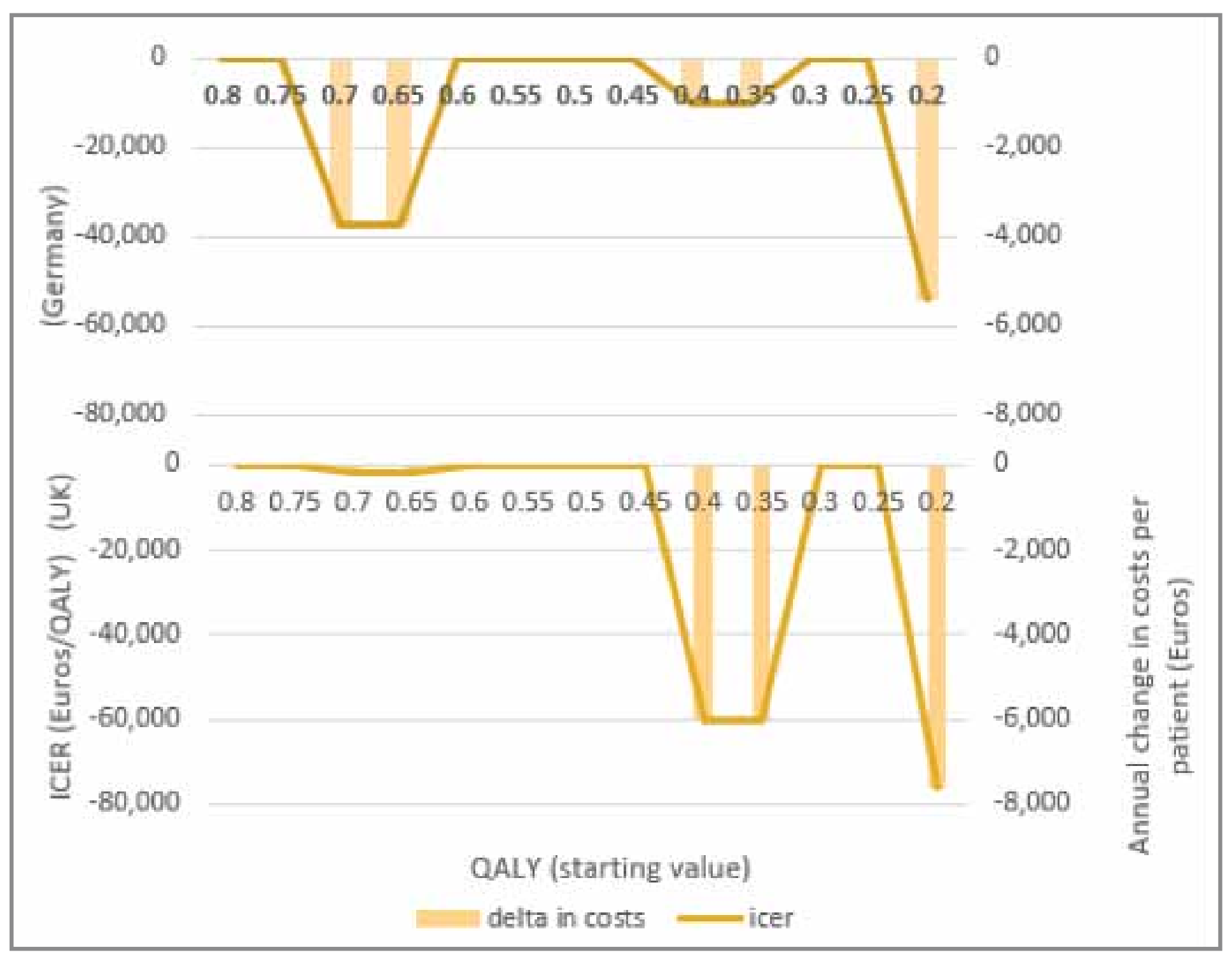


Figure 2: **Lack of early/timely treatment.** Economic impact of of a hypothetical treatment with fixed 0.10 QALY gain when given to patients at different health states (public providers’ perspective)

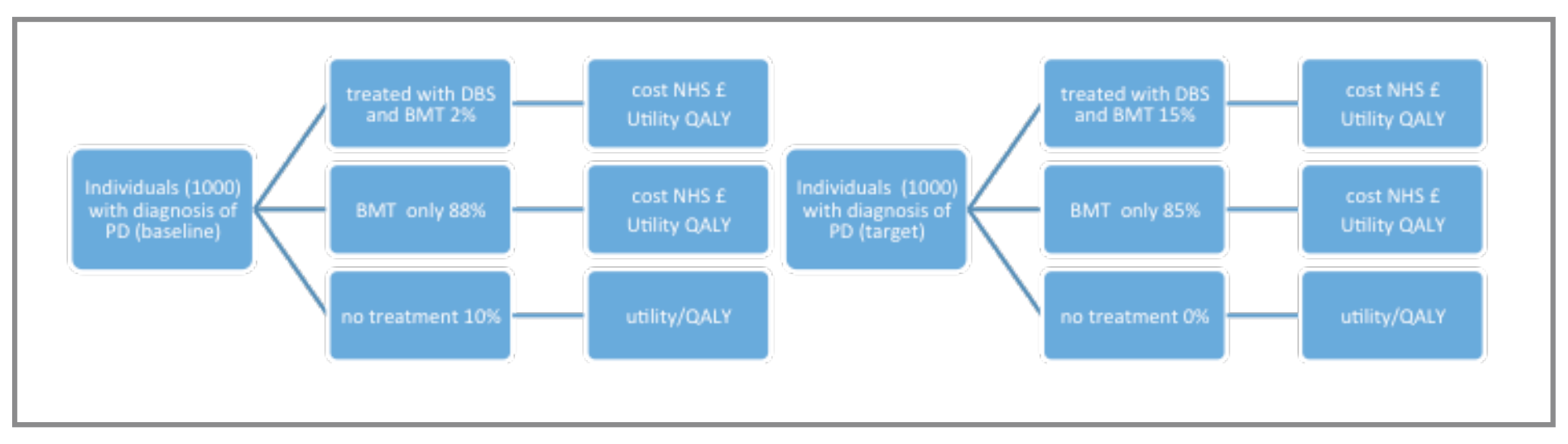
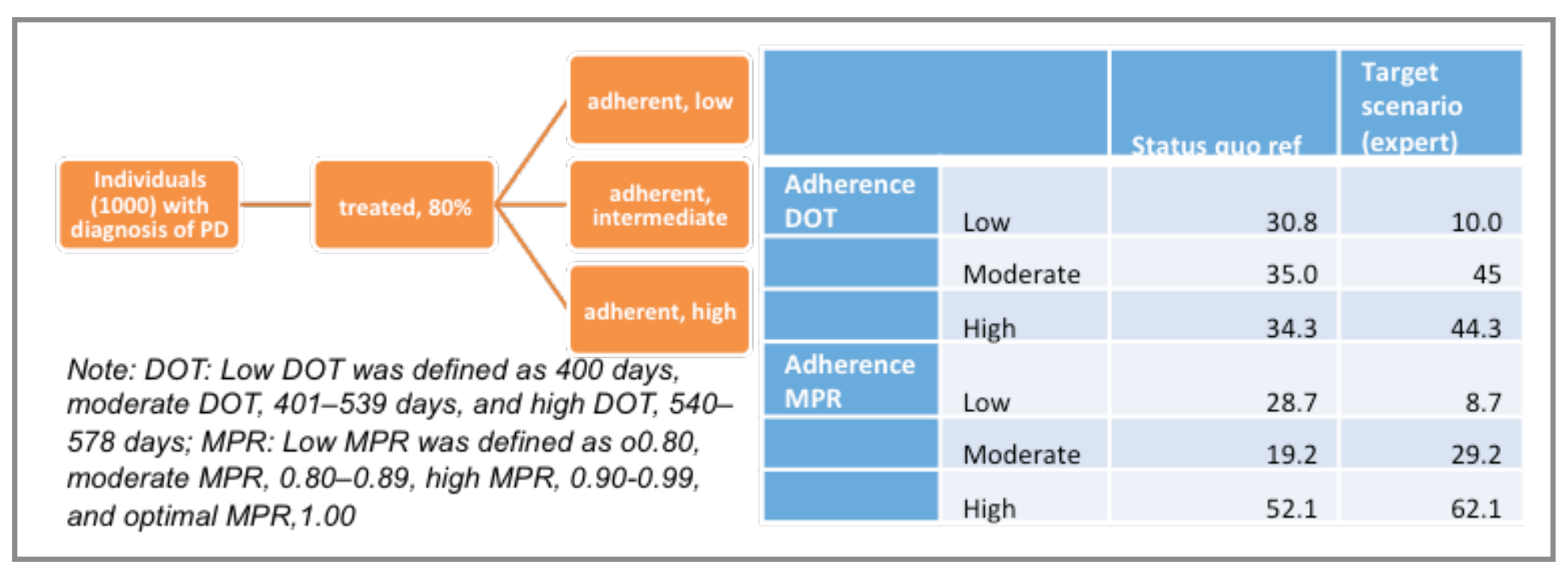


Figure 3: **Lack of adequate treatment for advanced PD.** Decision trees for the baseline and target scenarios

Country (source of data)	Scenarios	Cost per 1000 people (5 years; Euros, 2017)	QALY gain per 1000 people (5 years)	ICER
Germany (Dams[7])	Target	€ 38,041,643	3134	€ 14,836
	Baseline	€ 31,540,872	2696	
UK (Eggington[8])	Target	€ 64,369,795	1360	€ 32,681
	Baseline	€ 54,944,966	1072	
UK (McIntosh [9])	Target	€ 168,183,714	7145	€ 28,127
	Baseline	€ 138,680,392	6096	

Table 1: **Lack of adequate treatment for advanced PD.** Cost effectiveness of best treatment



Note: DOT: Low DOT was defined as 400 days, moderate DOT, 401–539 days, and high DOT, 540–578 days; MPR: Low MPR was defined as o0.80, moderate MPR, 0.80–0.89, high MPR, 0.90-0.99, and optimal MPR,1.00

		Status quo ref	Target scenario (expert)
Adherence DOT	Low	30.8	10.0
	Moderate	35.0	45
	High	34.3	44.3
Adherence MPR	Low	28.7	8.7
	Moderate	19.2	29.2
	High	52.1	62.1

Figure 4: **Lack of treatment adherence**. Decision trees for the baseline and target scenarios

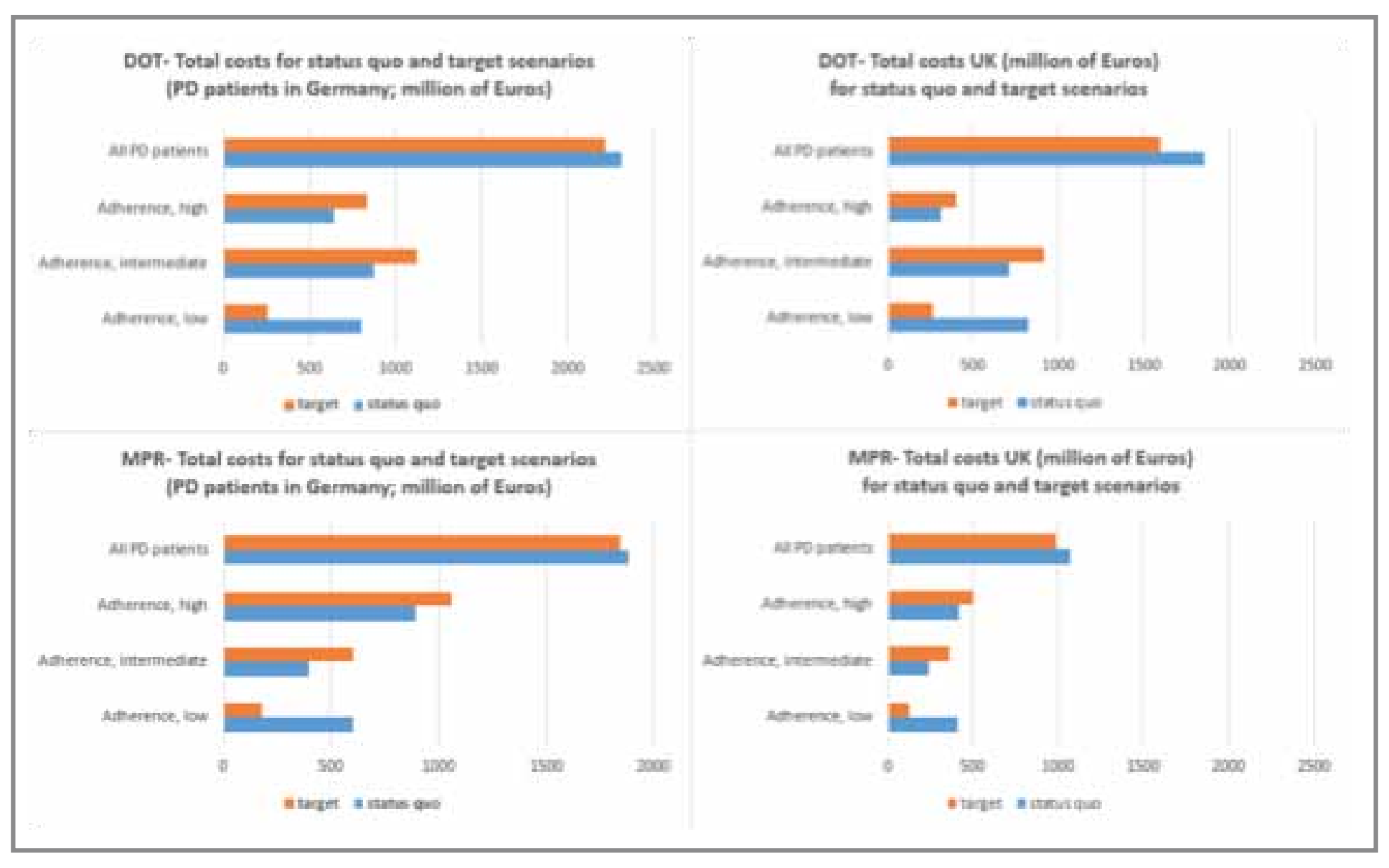


Figure 5: **Lack of treatment adherence.** Total costs for status quo and target scenarios (1000 patients, 2017 Euros, 1.5 years of treatment) (public providers’ perspective)