



## Diet in phenylketonuria: A snapshot of special dietary costs and reimbursement systems in 10 international centers

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### ABSTRACT

**Background and aims:** To gather exploratory data on the costs and reimbursement of special dietary foods used in the management of phenylketonuria (PKU) from ten international specialist PKU centers.

**Methods:** Experts from each center provided data on retail costs of the three most frequently used phenylalanine-free protein substitutes and low-protein foods at their center; reimbursement of protein substitutes and low-protein foods; and state monetary benefits provided to PKU patients.

**Results:** The mean annual cost of protein substitutes across 4 age groups (2 y, 8 y, 15 y and adults) ranged from €4273 to €21,590 per patient. The cost of low-protein products also differed; the mean cost of low-protein bread varied from €0.04 to €1.60 per 100 kcal. All protein substitutes were either fully reimbursed or covered by health insurance. However, reimbursement for low-protein products varied and state benefits differed between centers.

**Conclusions:** The variation in the cost and reimbursement of diet therapy and the level of additional state benefits for PKU patients demonstrates the large difference in expenditure on and access to PKU dietary products. This highlights the inequality between healthcare systems and access to special dietary products for people with PKU, ultimately leading to patients in some countries receiving better care than others.

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### 1. Introduction

For 60 years, the primary treatment for phenylketonuria (PKU) has been a low phenylalanine diet. Optimal dietary management of PKU includes administration of a phenylalanine-free protein substitute, supplemented with low-protein special foods, and close dietetic supervision and monitoring [1]. The economic cost of dietary treatment of PKU patients is unknown, and there is no publication describing the general access to protein substitutes or special foods, government benefits or other social allowances for PKU patients in Europe.

Within the EU, the composition of phenylalanine-free protein substitutes and low-protein foods are governed by the Foods for Special Medical Purposes directive [2]. This provides a single regulatory

framework and ensures consistent labeling and common nutritional standards to try to minimize trade barriers. In the EC directive, phenylalanine-free protein substitutes and low-protein foods are considered in the category of nutritionally incomplete foods with a nutrient adapted formulation specific for PKU. Within the EU countries, foods for special medical purposes may only be marketed if they comply with the rules laid down in the directive, but they still need to be approved according to the national guidelines of each country.

The dietary treatment of PKU varies throughout Europe [3] and this variation is also evident in the type of health professionals, qualifications, experience and allocated time available for the management of the PKU patients [4]. This variability in clinical treatment of PKU has a significant impact on the total cost of treatment across countries in Europe. The additional cost of phenylalanine-free protein substitute and the expenditure on special medical dietary foods may also vary. Although the clinical treatment costs are covered by the individual government budgets, the reimbursement of the dietary treatment cost and access to different

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dietary treatment formulas and special foods is likely to vary between countries. Some governments may expect patients or insurance companies to share some of the cost of dietary treatment.

As health and reimbursement authorities consider more carefully the cost of medical and dietary treatments, it is increasingly important to determine the expenditure on specialist dietary products for patients with PKU. Differences in costs between treatments, and countries, may have an impact on the relative perceptions these authorities have on treatment options and supplements. Currently there are limited data available to inform these decisions, so the objectives of this study were to conduct preliminary exploratory research into the costs associated with the treatment practices previously reported [4], the reimbursement status of PKU diet therapy and any additional social support patients with PKU received, in 10 PKU specialist centers. It is important to note that the study was not intended to provide a full economic analysis of the cost of therapy but designed only to provide some preliminary insight into the situation across different countries, forming an initial foundation from which decisions on the future direction for a more robust analysis can be made.

## 2. Materials and methods

### 2.1. Data collection

Ten established PKU experts at specialist PKU centers provided data about the types of protein substitutes and low-protein foods they used for the dietary treatment of PKU, all via a structured questionnaire. All respondents were selected based on membership of the European Nutrition Expert Panel on PKU. The respondents included nine dietitians and one physician and were located in Belgium, Denmark, Germany, Italy, Netherlands, Norway, Poland, Spain, Turkey and the UK. In a previous publication, the same 10 centers had provided information about their individual dietary practices for PKU [4].

The questionnaire included the retail price per package (in the local currency and converted to Euros where necessary) of the three protein substitute products most frequently prescribed to PKU patients at the ages of two, eight, fifteen and thirty years. These ages were chosen to represent the four progression phases of infancy, childhood, adolescence and adulthood. Each respondent also provided the retail price (per 500 g/200 ml) of the three most commonly used types of low-protein flour, low-protein pasta, low-protein bread and low-protein milk/milk replacements, along with details of any reimbursement available for low-protein foods. They described any state monetary benefits patients received to alleviate the cost of dietary management of PKU. All data was collected in January, 2009.

### 2.2. Statistical analysis

All analyses were assessed descriptively with costs in Euros based on January 2009 monetary exchange rates. Analyses included the mean annual cost (€) per patient of the three most frequently used protein substitutes based on the prescribed daily dosage calculated as grams per kg of body weight (dosage was based on country-specific and age dependent standards as previously reported by Ahring et al. [4]); the mean annual cost of protein substitutes for the ten participating centers (calculated as above); and the mean cost of low-protein foods based on the weight of food providing 100 kcal (calculated using the retail price per 500 g/200 ml provided by respondents and the energy content of each food type).

## 3. Results

### 3.1. Cost of protein substitutes across the ten centers

The single most expensive item in the dietary management of PKU was the phenylalanine-free protein substitute. The mean annual cost

of protein substitutes for each of the ten centers is detailed in Fig. 1. Mean values for the four age groups studied ranged from €4273 per patient in the Turkish center compared to €21,590 in the Spanish center.

A similar center distribution is shown when the mean annual cost of protein substitutes was analyzed by age group (two, eight, fifteen and thirty years), with the center in Turkey showing the lowest costs and the center in Spain the highest costs, (Fig. 2). However, there were exceptions; for example, in the center in Norway, patients aged two years and eight years cost the healthcare system more than those in the center in Spain. For adults, patients aged thirty years, centers in Poland and Turkey had equally low expenditures on phenylalanine-free protein substitutes.

Overall, the mean cost of protein substitutes increased at each of the age points (Fig. 2). The mean cost of protein substitutes of two-year olds across all countries was €5484, which rose to €9519 in eight-year olds, €13,278 in fifteen-year olds and €18,777 in thirty-year olds. There were exceptions; in Spain, the price decreased between the ages of fifteen and thirty years and in the UK the annual cost of protein substitutes for fifteen- and thirty-year olds remained the same.

### 3.2. Cost of low-protein foods across the ten centers

The mean cost, per 100 kcal, of the four important low-protein foods at each center is presented in Table 1, and it varied between centers. For example, the mean cost of low-protein flour varied from €0.10 to €0.37, that of low-protein pasta from €0.23 to €0.37; that of low-protein bread from €0.04 to €1.60; and that of low-protein milk/milk replacements from €0.27 to €1.37.

### 3.3. Government reimbursement of dietary products and state monetary benefits for patients with PKU

The levels of state benefit and reimbursement for low-protein foods across the 10 European countries are summarized in Table 2. All study countries fully reimbursed protein substitutes, except for the Netherlands and Germany, where the costs are covered by health insurance.

In contrast, special low-protein foods varied from being fully reimbursed to self-payment, depending on the center (Table 2). Only in two of the countries does the government fully reimburse the cost of low-protein foods, with patients in the UK and Italy receiving low-protein foods via a national prescription system. In Belgium, Denmark, Norway, and Turkey, patients receive monthly or annual financial allowances, which enable caregivers/patients to select any special low-protein food.

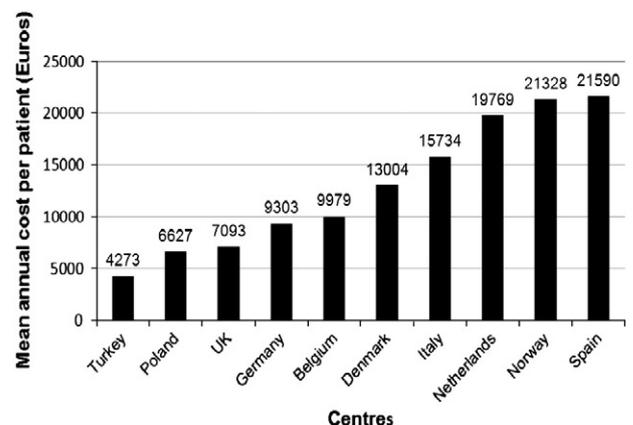


Fig. 1. Mean annual cost of protein substitute diet treatment annually per patient per center (€, 2009).

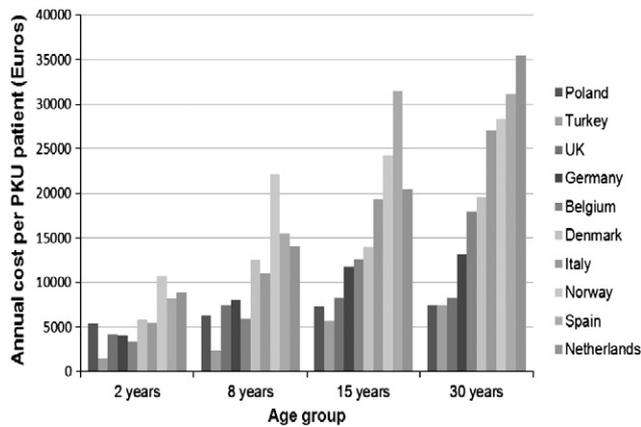


Fig. 2. Mean annual cost of protein substitute diet treatment for PKU patients in each center at age 2 years, 8 years, 15 years and 30 years (€, 2009).

State monetary benefits also varied between the ten European centers, with benefits ranging from annual state allowances for patients with PKU to no additional benefits (Table 2). In some countries, caregivers/patients with PKU are entitled to apply for life-long disability benefits (e.g., the UK and Belgium), whilst in other countries, support only continues up to the age of 18 years. Certain countries do not provide monetary benefits (The Netherlands) while others (Turkey, Spain, Denmark and Italy) provide various levels of non-monetary support including employment help, special schooling and home support. State benefits also take the form of funding for summer camps, specialist cooking equipment, travel allowances (for travel to specialist PKU centers) and transportation to schools.

#### 4. Discussion

Although the cost of special dietary products in PKU varied widely from center to center, all countries accepted reimbursement responsibility for some or all of the clinical foods used in PKU, either through subsidies or health insurance systems. Protein substitutes, an essential [5] but the most expensive component of dietary care, were funded in full by the respective health systems. In contrast, reimbursement policies for low-protein foods differed greatly from center to center. Overall, these findings indicate a generally good level of support for dietary treatment of PKU patients across centers studied, especially considering the increasing financial challenges faced by individual countries through the introduction of new technologies and drug treatment, aging populations and rising expectations of caregivers and patients, all competing with the cost of diet therapies.

Only two countries issued their protein substitutes via an insurance system. This included the Netherlands, where everyone resident or paying income tax is required to purchase health insurance coverage under the Health Insurance Act [6]. It also included Germany, which, at the time of the study had a publicly-financed (social) health insurance compulsory for people earning less than a set minimum income, which covered approximately 88% of the population (the rest obtained private health insurance or remain without insurance) [7]. Recent developments in the German healthcare system mean that as of 2011 almost all of the population is covered under statutory

health insurance [8], the impact of this change on the reimbursement of protein substitutes has yet to be studied.

The retail price of phenylalanine-free protein substitutes varied widely from center to center. The type, dosage, and composition of the three most frequently-used protein substitutes at each center were factors in this price variation, as was patient age, however several other factors might also affect retail price variations. Country-specific policies and preferences also affect the retail cost of protein substitutes. In the UK, for example, the Advisory Committee on Borderline Substances places a ceiling price on protein substitutes. This controls the cost of all phenylalanine-free protein substitutes; thus, products in the UK had similar costs when compared by their protein equivalent content. Transport, handling and distribution costs may also affect retail price, although there should be no additional 'export duty' for selling protein substitutes between EC countries. The volume of product used by an individual country is also a factor; generally, the higher volume of protein substitute used, the lower the cost of product. The high price of protein substitutes in Norway may reflect the overall cost of living in this country, which is the most expensive country in Europe [9].

Availability of protein substitutes varied between countries; for example, in Turkey, only a limited range of traditional and cheaper products were available. Of the 10 centers studied, those within EC countries and Norway used similar protein substitutes for PKU, and they were more likely to use protein substitutes that had been introduced within the last 10 years. While the latest protein substitutes are more expensive, they also have improved palatability, nutritional composition and presentation and are associated with better long term patient adherence, metabolic control and nutritional outcome [5,10,11].

In terms of low-protein foods, reimbursement policies and costs for low-protein foods were notably inconsistent across the ten centers. Reimbursement varied from full reimbursement in Italy and the UK (with a mandatory prescription payment for those over the age of 16 in the UK), to monthly allowances in Belgium, Norway and Denmark, to self-payment in Spain, Germany, The Netherlands and Poland. The overall cost of low-protein foods differed between products. The mean cost of low-protein milk replacements per 100 kcal was several times more expensive than the cost of low-protein flour; the mean cost of low-protein bread and pasta per 100 kcal was almost twice as expensive as low-protein flour. The overall expenditure on low-protein foods depends on the quantity of each product that is consumed by the individual patient; this, in turn is influenced by their age, appetite, food preferences, energy requirements and the amount of natural protein tolerated. The mean costs of the four main low-protein products (flour, pasta, bread and milk) also varied greatly from center to center; for example, low-protein bread costs per 100 kcal ranged from €1.6 in Belgium to €0.17 in Poland and €0.04 in Turkey. With some exceptions, the mean cost of low-protein foods appeared to be influenced by the local reimbursement system, with centers where patients were expected to self-finance low-protein products (Poland, Spain, Germany and Netherlands) reporting lower costs for bread, flour and pasta.

The differences in reimbursement for and access to low-protein foods reflect the diversity of the healthcare systems throughout Europe. In the UK, where the costs of low-protein foods are higher and mainly reimbursed by the publicly-funded National Health Service, patients

Table 1  
The mean cost (€) per 100 kcal of the four main low-protein products for each center.

	Belgium	Denmark	Germany	Italy	Netherland	Norway	Poland	Spain	Turkey	UK
Low protein flour	€0.23	€0.20	€0.20	€0.37	€0.17	€0.20	€0.13	€0.10	€0.21	€0.37
Low protein pasta	€0.33	€0.33	€0.27	€0.30	€0.26	€0.37	€0.27	€0.13	€0.33	€0.34
Low protein bread	€1.6	€0.6	€0.23	€1.0	€0.43	€0.65	€0.17	€0.3	€0.04	€0.36
Low protein milk	€0.53	€1.13	€1.37	€3.5	€1.13	€0.4	€1.13	€0.27	€1.25	€1.32

**Table 2**

Reimbursement status of low protein foods and the provision of state monetary benefits in the 10 centers studied.

	Reimbursement of low-protein foods	State monetary benefits for PKU dietary management
Belgium	✓ Financial allowance of up to €1834 per annum. Freedom to choose preferred foods Dispensed in pharmacies only.	✓ Patients receive disability allowances
Denmark	✓ Financial allowances of between €91–198 per month, dependent on age. Freedom to choose preferred foods.	✓ Patients are funded to go to summer camps, are given dietary allowances, receive home support or compensation to parents for decreasing working hours for up to 10 h per week and financial help toward essential cooking equipment.
Germany	✗ Reimbursement only in special cases (e.g. welfare recipients).	✓ Patients can apply for a disability (handicapped ID) with tax benefits
Italy	✓ Fully reimbursed. Dispensed in pharmacies only.	✓ Patients can apply for a disability certificate which helps with employment.
Norway	✓ Financial allowances of between €97–188 per month, dependent on age. Freedom to choose preferred foods.	✓ All PKU patients under 18 years receive state allowance of €114 per month. Travel expense to PKU centers are reimbursed.
Netherlands	✗ No government funding, however those on a low income or who are unemployed are given a certain amount of money each month from social services to cover these foods.	✗ No additional benefits
Poland	✗ No government funding. Products can be purchased at food markets, over the internet as well as in the pharmacy.	✓ Every PKU patient under the age of 16 years and those in low-income families, receive state allowance
Spain	✗ No government funding, however a PKU Parents Association buys all low-protein products and provides patients with a 15–30% discount (wholesale prices) or for free	✓ Patients can apply for a disability certificate which helps with employment, educational grants and travel expenses to PKU centers.
Turkey	✓ The government funds a monthly age-dependent financial allowance. Based on a 2011 Euro exchange for Turkish liras, the allowance varies between 13.6 (aged: 0–12 months) to 35.1 (aged: > 15 years 35.1) Euros monthly.	✓ The government funds special schooling for those with learning difficulties and transportation to schools.
UK	✓ Fully reimbursed, however those over the age of 16 pay a prescription charge. Dispensed via pharmacists only.	✓ Patients may receive disability allowances either at a low, middle or high rate. Each patient has to apply individually.

older than 16 years are expected to make a co-payment for prescription charges [12] (€8.46 per prescription from April 2011). In addition, UK patients only have reimbursed access to about 50% of the special low-protein foods available internationally and the National Society for PKU has issued guidance on the age-related maximum quantities of low-protein foods that should be prescribed [13]. In countries such as Turkey, an age-dependent financial allowance is allocated to families to purchase low-protein foods, but the monthly allowance is limited.

Social welfare systems across these 10 countries are also diverse; again, this diversity is reflected in the disparity in additional monetary and non-monetary benefits given to PKU patients. For example, in Denmark, patients can apply for generous disability allowances per annum; however, in the Netherlands, there are no additional monetary benefits. Although monetary benefits might help ease the financial burden of dietary management of PKU, there is no research demonstrating that financial benefits are effective as an intervention in improving outcomes for patients with PKU. Therefore, some countries use non-monetary benefits, such as home support and special cooking equipment, to promote better outcomes. Financial details and eligibility criteria for additional monetary allowances were not studied.

This study had limitations. The branded products used varied by center and the costs of dietary products collected were retail prices, which may not necessarily be the same as the reimbursed price paid by healthcare providers as it is acknowledged that there may be contract discounting involved. However this is unlikely to be the cause for all variation in price. In addition, the selection of centers and dietitians was based on invited membership to the European Nutrition Expert Panel on PKU, and is not representative of all Europe. Note also that the management policies and practices at the selected centers may not necessarily represent the national policies of their respective countries. Our data do not include the cost of clinical management, blood

phenylalanine monitoring, nutritional assessment, growth monitoring or the cost of monitoring biochemical nutritional markers. However, the data do reflect expert opinions in PKU and do provide an indication of the costs of dietary management of PKU in the countries studied. When considering these findings it is also important to note that this research was not intended to be a full economic study and thus does not stand up to a rigorous review reserved for such analyses. The study was only intended to provide an initial view of how the situation might vary across different countries and systems, thus forming a foundation for future decision making and subsequent economic research.

The results from these centers suggest that there are enormous variations in expenditures on and access to PKU dietary products across the 10 countries; varying costs for protein substitutes and low-protein food as well as varying reimbursement policies and additional state benefits for patients with PKU contribute to these discrepancies. The variation in reimbursement identified here is supported by information recently published on the European Society for PKU website listing reimbursement policies in the different countries in Europe [14]. This highlights the inequality that exists between healthcare systems and access to special dietary products for people with PKU, which ultimately leads to patients in some countries receiving better care than others.

In the current economic climate, where healthcare authorities must carefully examine the cost of care, there is a strong need for future research to fully quantify the economic burden of dietary treatment for PKU to healthcare systems and society. This research should include not only direct healthcare costs, but also indirect costs to caregivers, such as lost income due to additional child care and preparation and supervision of dietary treatment. This research would be particularly valuable when assessing new drug treatment options for PKU, and will allow healthcare authorities to make fully informed decisions about treatment opportunities for patients with PKU.

### Conflict of interest statement

ABQ has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono, and has provided paid expert testimony for Mead Johnson and Cassen.

KD has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono.

HGO has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono, and travel/accommodation expenses for meeting attendance funded by Vitaflor.

AML has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono.

AM has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono. She also has received funding from Vitaflor and Nutricia for research.

KM has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono, and honoraria for lecturing at international and national meetings for SHS International and Vitaflor.

MN has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono. MN is not currently a member of European Nutritionist Expert Panel in PKU.

MR has received honoraria and travel/accommodation expenses for advisory board attendance funded by Merck Serono, and travel/accommodation expenses for meeting attendance funded by Vitaflor.

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### Statement of authorship

ABQ, KD, AML, AM, KM, MN, MR, MvR, and KA designed the study and conducted the collection and analysis of data, as members of the European Nutritionist Expert Panel in PKU. AM led the manuscript development, and all authors read and approved the final manuscript.

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