



Consultation:

The Green paper on Ageing – Fostering solidarity and responsibility between the generations

Response from:

ESP KU (European Society for Phenylketonuria and Allied Disorders Treated as Phenylketonuria) European Parliament Cross-Party Alliance on PKU

SUMMARY

What can active and healthy ageing policies do for people living with PKU?

- Ensure affordable access to appropriate care regimes throughout life
- Ensure universal access to new born screening, to enable a healthy start in life and prevent avoidable neurological/ mental health issues
- Ensure implementation and monitoring of European guidelines on minimum standards of care
- Facilitate equal access to appropriate dietary and pharmacological therapy and innovation
- Facilitate clear and accurate protein food labelling to facilitate adherence to the required diet

Introduction

The European Society for Phenylketonuria and Allied Disorders Treated as Phenylketonuria (ESP KU) and the European Parliament Cross-Party Alliance on PKU warmly welcome the opportunity to express our views in relation to the Commission's Green Paper on Ageing, which aims to launch a broad policy debate to discuss how to anticipate and respond to current and future demographic challenges and opportunities. This document sets out our views on why and how healthy and active ageing policies matter to people living with phenylketonuria (PKU) and the measures that can be taken to ensure healthy and active ageing becomes a reality for patients and their families.

Who are we?

The ESP KU was founded in 1987 as a patient-driven non-profit umbrella organisation representing PKU organisations across Europe. It currently consists of 41 national and regional associations from 31 countries. The ESP KU acts as the coordinator of the **European Parliament Cross-Party Alliance on PKU**, which was launched in March 2020 with the aim to:

- bring together MEPs (and relevant) stakeholders to raise awareness of and propose and advocate specific (policy) initiatives to better address unmet needs in PKU across the EU;
- ensure that individuals affected by PKU and their families have lifelong access to the services, therapies and support to best manage the disorder and its daily impact.

What is PKU?

There are currently approximately 45,000 people in Europe living with PKU - a rare metabolic condition diagnosed through newborn screening. PKU affects a person's ability to break down phenylalanine, an amino acid present in protein. When phenylalanine builds up in the bloodstream, it can lead to intellectual and physical disability. Treatment consists of a protein restricted diet for life; however, research has demonstrated that adherence to dietary therapy as well as access to the foods required is a challenge for many people living with PKU. Pharmacological therapies with proven efficacy are available - but not to all individuals with PKU.

PKU can have lasting neurological, emotional, mental health and behavioural consequences. Moreover, it affects all dimensions of an individual's life as well as that of their families and carers. Co-morbidities (osteoporosis, high blood pressure, obesity, asthma, chronic ischemic heart disease) are common.



General remarks

PKU is increasingly recognised by policymakers as a condition which needs attention. However, continued efforts are required to anchor it as a public health priority on the EU and national policy agendas, by exploring all avenues for policy action to improve the lives of those living with the condition.

The consultation on the Green Paper on Ageing is such an avenue, and we warmly welcome this initiative and the balanced stance it is taking in terms of the challenges as well as the opportunities with respect to societal ageing.

In addition, ESPKU and the Cross-Party Alliance welcome the Green Paper's life-cycle approach – rather than focus on old age only - reflecting the universal impact of ageing, as well as its focus on the personal and the wider societal implications of ageing. It is positive to note that the Commission is putting demographic developments and their implications high on the EU policy agenda.

We also welcome the Paper's reference to the European Pillar of Social Rights and its Action Plan, setting out a number of principles that relate directly or indirectly to areas impacted by ageing, e.g., long-term care, health care, and inclusion of people with disabilities. The Action Plan is intended to stimulate the development of the required policy responses to address demographic challenges; such as preventative measures to avoid ill health along the life cycle and the need for high-quality, accessible and long-term care. It also recognises the case for inclusion and empowerment and will provide guidance to Member States on how to ensure equality and equity within our societies.

Specific remarks

The need for access to appropriate healthcare and services throughout life

Growing older in the best possible health also relates to having access to appropriate, affordable and quality services throughout life. PKU is often – erroneously - seen as a paediatric condition. As a result, adequate transition regimes from child to adult care are lacking in many countries. This means that in many cases, patients get lost to follow up and go 'off the radar', with all the negative consequences that this entails for their mental and physical health and well-being. A recent German study shows that some 20% of adult PKU patients are lost when making the transition from child to adult services; this means that, in practice, patients

are continuing to be seen in children's clinics in order not to lose them, which exposes them to a situation of no or inappropriate care. While pragmatic, this clearly does not constitute 'appropriate care'.

PKU needs to be recognised as a life-long condition; appropriate services, health care, treatment (including equal access to pharmacological innovation, as stated as a general priority in the recent new EU Pharmaceutical Strategy) and transition regimes should be put in place, in consultation with patients and their representative organisations. ESPKU's European PKU treatment guidelines, spelling out minimum standards of care for people living with PKU can be helpful in this respect.

While we agree that healthy and active ageing is a personal choice and responsibility as stated in the Paper, it is also true that it depends heavily on the environment in which people live, work and socialise. In the case of PKU, proactive measures – such a new born screening, access to dietary therapy and implementation of appropriate treatment guidelines providing guidance on minimum standards of care (currently being updated and revised) – are determining factors to 'help ensure that healthy and active ageing becomes an easier choice, including for those in situations of vulnerability'.

In this context it is also important to highlight the need for improved access to pharmacological and innovative therapies, as these can greatly enhance and contribute to quality of life, both of patients as well as families.

The need to cater for the unknown needs of older people living with PKU

As a result of new-born screening, dietary and pharmacological treatment, the first generation of older PKU patients will reach old age in the next decade.

It is therefore not yet known if there will be further complications in old age – for instance, as a result of years of adherence to a strict diet – and what the care needs consist of. In addition, there are gaps in knowledge with respect to the impact of PKU on the ageing body and mind. Long-term international collaborative studies are required in order to have clarity on these issues. What is already clear is that healthcare and long-term care systems will need to respond to this potential new care demand.

We therefore fully agree with the Green Paper's statement on the need for a 'comprehensive policy response, investing in quality services and infrastructure, as well as in healthcare research and innovation, ensuring the access to healthcare across the board'.

Member States already face common challenges in long-term care, which include ensuring access, and quality, of long-term care. However, quality long-term care is important to ensure personal dignity, choice and well-being. Currently, there are different quality standards and interpretations across the EU and Member States are at different stages of quality assurance. Again, ensuring the implementation of guidelines stipulating minimum care standards can provide support for patients as well as for care providers across the board.

As the care needs and services for older PKU patients are currently still unknown, research and careful monitoring would be required to ensure that they enjoy the highest possible quality of life.

The need for genuine and universal access to new-born screening

The Green Paper rightly states that the years from early childhood to young adulthood 'affect us for the rest of our lives and that laying the right foundations early on can help prevent, limit and postpone some of the challenges linked to ageing'.

This is particularly relevant in the context of PKU as, by means of new-born screening, PKU can quite easily be detected – and therefore treated. In other words, access to new born screening is absolutely essential as it determines all elements of the life course and quality of life of persons living with PKU. While access to new-born screening is in place in many EU countries, there are marked access differences across the EU.

The need to ensure access to dietary therapy and sound food labelling

The Paper also highlights that healthy and active ageing is about 'promoting healthy lifestyles throughout our lives; this includes our consumption and nutrition patterns and our levels of physical and social activity'.

Having access to the appropriate dietary treatment and products is crucial for people living with PKU. The diet is strict and severe as protein intake is highly restricted: people living with PKU cannot eat meat, fish or dairy products. The diet is also difficult to adhere to when socialising with friends (e.g. children's birthday parties, going out to dinner with friends...) and because the products required are not always available or affordable.

Furthermore, while it is imperative for patients to have accurate information about the composition of their food, current food labelling practice does not take sufficient account of the information required by persons adhering to the strict PKU diet.

In conclusion

The ESPKU and the European Parliament Cross-Party on PKU would like to again thank the Commission for the opportunity to share our views and concerns about people living with PKU and their families.

We ask for these to be considered in the next steps and follow up to the Green paper; and of course, we would be happy to provide any more information and data required and work with the Commission to ensure healthy and active ageing for people with PKU.

This response was sent on behalf of the European Parliament Cross-Party Alliance on PKU and the European Society for Phenylketonuria and Allied Disorders treated like Phenylketonuria (ESPKU).

The Cross-Party Alliance on PKU is supported by the following MEPs:

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