

## Perception of Social Assistance in the Daily Life of Rare Metabolic Patients

### Introduction

**Welcome to the survey on patients' perspectives on social assistance needs.**

**“Quality of life is very important for patients, and in particular for patients who suffer from rare or unknown disorders”**

**Who is this survey for?**

**All rare metabolic patients and/or their caregivers can participate, as long as they are at least 18 years old. Only one survey per patient.**

**What is the main aim of this survey?**

**To understand the differences in social assistance needs of patients affected by rare metabolic disorders in Europe.**

**What will the main outcomes of this study be?**

- **to have a clear picture of the European social assistance landscape/measures regarding rare metabolic patients;**
- **to know the social assistance needs of patients;**
- **to inform patient associations on this topic and empower them to lobby for social assistance measures in their country.**

**How long will it take me to complete this survey?**

**The survey contains 46 questions and should take roughly 15 minutes to complete.**

**By completing the survey to the best of your ability, you will help us to build a complete and representative data set for these important purposes.**

**Who developed this study?**

**This survey was developed by MetabERN, the European Reference Network on Rare Hereditary Metabolic Disorders and particularly by the members of Work Package 6.**

**Learn more about MetabERN [HERE](#).**

## What will you do with my data?

All answers are anonymous. Answers will be collected and analysed by the MetabERN central office. The individual responses will not be shared with any third-party entities, with the exception of Survey Monkey. At the end of the analysis, the conclusions will be returned to the healthcare providers and patient associations in MetabERN, and if the study is conclusive then it may be published and/or a report will be posted on the MetabERN website. The findings of the study will be shared with other ERN teams and the European Commission officers (DG Santé). The Survey Monkey privacy policy and cookie policy is accessible at the bottom of the survey home page.

## Do you have any further questions?

Contact [cinzia.bellettato@metab.ern-net.eu](mailto:cinzia.bellettato@metab.ern-net.eu)

## Deadline:

## By clicking "agree" you confirm:

- you have read and understood the previous information;
- you voluntarily agree to participate;
- you are at least 18 years of age;
- you are a rare metabolic patient yourself or a family member/caregiver of someone living with a rare metabolic disorder.

\* 1. Please indicate your choice below:

- Agree
- Disagree, and by doing so I refuse to participate in the survey

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\* 2. Are you?

- A patient
- A parent
- A caregiver/relative of a patient

\* 3. Are you?

- Male
- Female

\* 4. What country do you live in?

\* 5. What is the name of the rare metabolic disorder that you/or the patient is affected by?

\* 6. How old are you (the patient)?

- Under 18
- Over 18

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### Your town/city

**This section is to gather information about services offered in the place that you live.**

7. In your city/town, is there a reference contact point (office, institution) for access to local, regional or national government benefits and services?

- Yes
- No
- I don't know

8. Are public buildings accessible to disabled people?

- Yes, all
- Some
- No
- I don't know

9. Are there disorder-specific medical services, specialised in your disorder, available in your area?

- Yes
- No
- I don't know

10. Are there emergency services, specialised in your disorder, in your area?

- Yes
- No
- I don't know

11. In your country's health system is there a particular pathway dedicated to your disorder area, to which a patient is assisted from diagnosis up to starting treatment, to follow-ups and annual tests, etc?

- Yes
- No
- I don't know

12. Is your metabolic consultant/specialist or a member of their team easily accessible?

- Yes
- No

13. Do you (the patient) need food supplements or dietary supplements?

- Yes
- No
- I don't know

14. In your (the patient) case, is home care necessary?

- Yes
- No

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15. Is the cost of home care covered by the government?

- Fully
- Partially
- Not at all

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16. What is your level of satisfaction with the following aspects of home care?

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
Range of care offered	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having blood and other types of samples collected (e.g. urine) at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical home examinations/appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scheduled home visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physiotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other types of at home therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other types of at home therapy (please specify)

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17. Are the services of a social worker guaranteed?

- Yes
- No
- I don't know

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18. Rate your satisfaction with **social work services**.

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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19. Is psychological assistance available?

	Yes	No	I don't know
For the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For parents/caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Do you think that psychological assistance is necessary?

	Yes	No	I don't know	Not applicable
The patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents/caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. Are physiotherapy services easily accessible in specific medical facilities, such as hospitals, physiotherapy centres, private institutions?

- Yes
- No
- I don't know
- Not applicable

22. If you use a physiotherapy service, how many sessions a week do you do?

- Less than 1
- 1
- 2-3
- 4-5
- More than 5
- Don't use

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23. If you do not use the physiotherapy service, how many sessions per week would you need?

- Less than 1
- 1
- 2-3
- 4-5
- More than 5
- Don't know

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24. Are all necessary physio-therapies (e.g. pre or post-rehabilitation) approved and made available by the health service or must they be carried out on a privately-paid basis?

- Fully covered
- Partially covered
- Not covered
- Don't know
- Not applicable

25. In the case of using the private sector, why is it necessary to do so?

	Yes	No	Don't know	Not applicable
There is no specific therapy covered by health service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health-service cover is insufficient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The need for that therapy is not recognised by the referring physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. Do you (the patient) suffer from an intellectual disability?

- Yes
- No

27. In the case of mental disability, what kind of educational and development programs are offered in your country, at no cost, by any government department or non-government institution/organisation?

	Yes	No	I don't know	Not applicable
A home educator	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Special needs school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A day care centre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychomotor skills development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autonomy building structures or organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tutor for job placement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specific vocational training programmes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family houses (assisted independent living group home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other, any service provided by any government you perceive as appropriate to the education/development of the patient (please specify)

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### School-age patients

**This section is for school-age patients.**

28. Is the patient at school?

Yes

No

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32. Is extra assistance related to the patient's condition provided, for the following?

	Yes	No	I don't know	Not applicable
pre-school feeding assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
junior school feeding assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
senior school feeding assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
transport service for the school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

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### Transition from childhood to adulthood, and available facilities and jobs

**This section is for patients transitioning from childhood to adulthood as well as those who are adults and are looking for work.**

33. Is the patient transitioning from childhood to adulthood?

- Yes
- No

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34. Regarding the transition from childhood to adulthood

	Yes	No	I don't know	Not applicable
Are gathering places for young people in your city accessible to people with disabilities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are autonomy-building structures or organisations provided?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are specific vocational training programs planned/available?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is social-therapeutic placement offered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are family houses available?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are there specific autonomy-development pathways?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there the possibility of access to independent life experiences?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there personal psychological support for you (the patient)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there personal psychological support for parents/caregivers/other?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

35. Is there any economic support (e.g. special deductions) provided by the local, regional or national government in the case of a disabled person in a family, such as?

	Yes	No	I don't know
discount on electricity bills, heating expenses, taxes etc	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
allowance for independent living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
allowance for non-self-sufficiency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

36. Have you (the patient) obtained recognition of civil disability?

- Yes
- No

37. On the board that determines such recognition, is the presence of an expert doctor in rare diseases required?

- Yes
- No
- I don't know

38. Is civil disability recognition necessary to easily obtain services/facilitations like?

	Yes	No	I don't now
awarding of a disabled parking permit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
access to specific areas of public transport	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
accompanying allowance (sum provided by government specifically to pay for a personal assistant)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
discounts on the purchase of food products (supplements, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
discounts on the purchase of medical devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

39. Are you (the patient) currently employed?

- Yes
- No
- Not applicable

40. How long did it take you (the patient) to find a suitable job position (from the moment you started job hunting for the first time)?

- less than 3 months
- less than 6 months
- less than 1 year
- less than 2 years
- over 2 years
- I'm currently unemployed
- Not applicable

41. Are job opportunities made available in the public sector for patients with various types of limitations?

- Yes
- No
- I don't know

42. What support is given in the workplace for you (the patient) to facilitate your employment?

	Yes	No	I don't know
Are there any workplace facilitations (aids, etc.)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is part-time/flexible schedule possible (e.g. home based work)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are health and hospitalisation needs recognised? (e.g. medical appointments)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

43. Have central or local governmental institutions developed "After Us" projects? (Being projects to address the issue of care for the patient after parents/relatives/caregivers have died or are incapacitated)?

- Yes
- No
- I don't know

44. Are these After Us projects or equivalent developed in your country?

	Yes	No	I don't know
By state departments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With the collaboration of other institutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With the support of patients associations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

45. How is the "After Us" projects or equivalent financed?

	Yes	No	I don't know
Completely dependent on the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Partially dependent on the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paid for by the government/public funds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wholly supported (covered/paid) by patient associations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Final question

**Please see question below.**

