







Network
 Hereditary Metabolic
 Disorders (MetabERN)

GIOVEDÌ 22 APRILE 2021 dalle 11.00 alle 13.00

EVENTO DEDICATO ALLA MALATTIA DI ANDERSON-FABRY e PRESENTAZIONE DEL CARTONE ANIMATO



L'impatto del Covid-19 sui pazienti: l'indagine Europea

Relatrice: Dott.ssa Cinzia Maria Bellettato – MetabERN

BG

DE

HR

HU

MetabERN Geographic Coverage MetabERN Full Member MetabERN Affiliated Partner **69 Health Care Providers** + 9 APs = 78 HCPs from 23 COUNTRIES +New Call 2019 24 **=TOTAL???!!!** 78 Health Care Providers from 23 COUNTRIES

NL



Network Hereditary Metabolic Disorders (MetabERN)



for rare or low prevalence complex diseases

Network Hereditary Metabolic Disorders (MetabERN)

METABERN MULTIDISCIPLINARY TEAM (MDT)



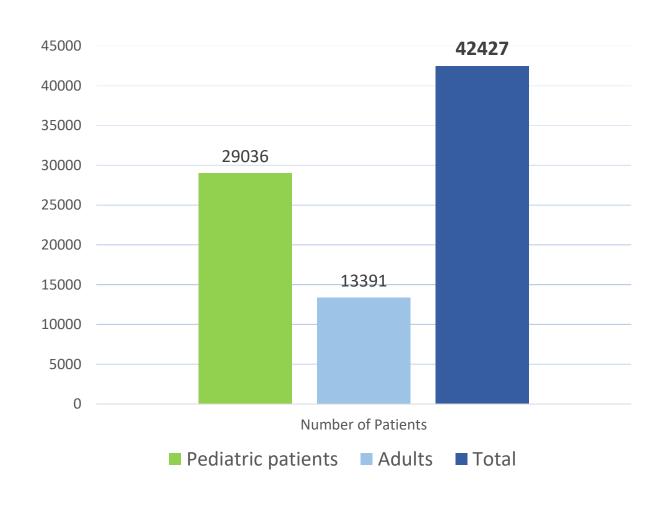
- 871 Specialized Medical Doctors
- 188 Biochemists/Biologists
- **184** Nurses
- 121 Dieticians/Nutritionists
- **76** Physical therapists/Rehab
- 73 Psycologists
- 49 Social workers
- **34** Pharmacists
- **34** Coordinators/Medical Secretaries
- 13 Experts in Palliative care/Pain management
- 10 PHD/students
- 28 Other

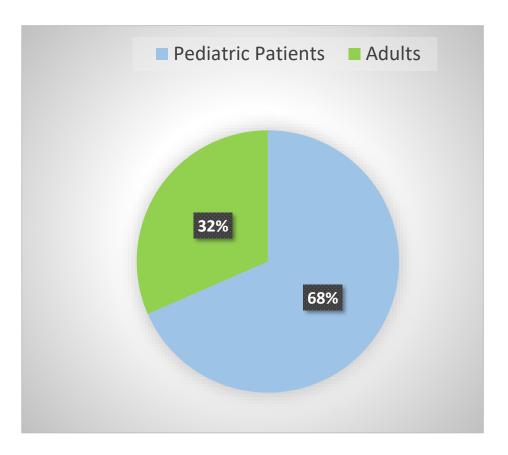
a Total of
1681
Experts



MetabERN: Patients Coverage



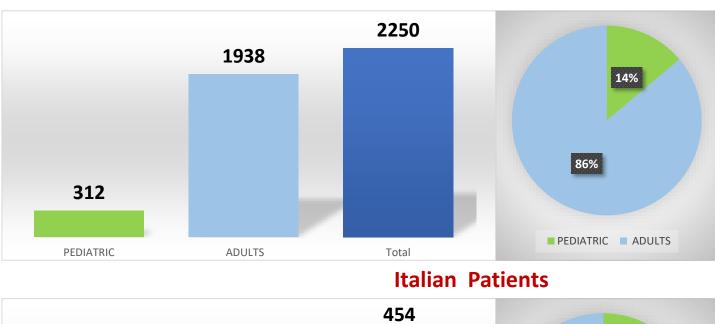


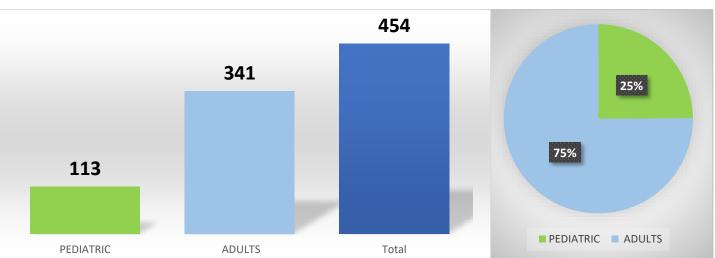


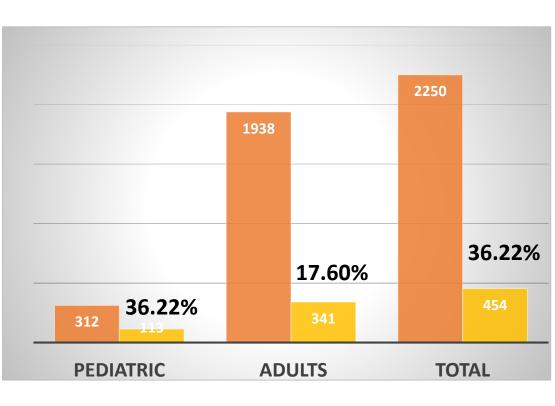


Patients with Fabry followed by MetabERN

Total Patients







MetabERN: How we share, how we care

- Enhance speedy diagnosis by promotion of diagnostic expert consultation (CPMS) and training sessions
- Improve access to the best diagnostics (biochemical/genetic) and to genome-wide genetic investigations through active collaboration with Orphanet and ERNDIM

Prevention

Screening

Diagnosis

Treatment & Facilitation of access to the best diagnostics

Follow up

- Participate in and provide input and insights from patients and HCPs in **Education of patients**
- Instruct general practicioners on how to follow patients
- Promote the MetabERN Education website (https://metab.ern-net.eu/) dedicated to capacity-building, education & training.
- Continue collaboration with **other ERNs** through the ERN-Coordinators Platform (on a strategic level) and through on-going consultations with overlapping networks (at a practical level)

- Increase **awareness** amongst general public and Health care professionals, health authorities and relevant stakeholders on inherited metabolic disease (IMDs)
- Dissemination of new and revision of existing health information, scientific publications
- Facilitate and harmonise the **newborn screening** in EU
- Use of the Unified-IMD registry to study the **natural history** of asymptomatic and symptomatic state of diseases
- Revise/develop of Care pathways & Guidelines
- Facilitate **Clinical Trials/Research** (defining research priorities and disseminating research related information)
- · Create big databases with patients data
- Improve the Regulatory process for medicines
- Participate in the production of White papers and Recommendations
- Assess the effectiveness and efficiency of clinical processes
- Develop a common programme on Transition from childhood to adulthood

Education and Training needs

Social framework

Inclusiveness

Patient Empowerment

ALL WITH ONE GOAL IN MIND: OUR PATIENTS!

- Share the 'Quality of Life' surveys and outcomes measurement
- Facilitate the provision of social care services

Recent achievements to start the journey:

- A dedicated group on patient empowerment has been established
- The Patient Board governance structure is up and running including the Patient Executive Committee (PEC). The PEC is the voice of all patient representatives involved in the subnetworks and Work Packages in order to improve their involvement and enable their feedback to be heard by HCPs.
- Patients have been involved in addressing their specific needs, preferences and priorities (Survey, feedback systems, etc.)



olio

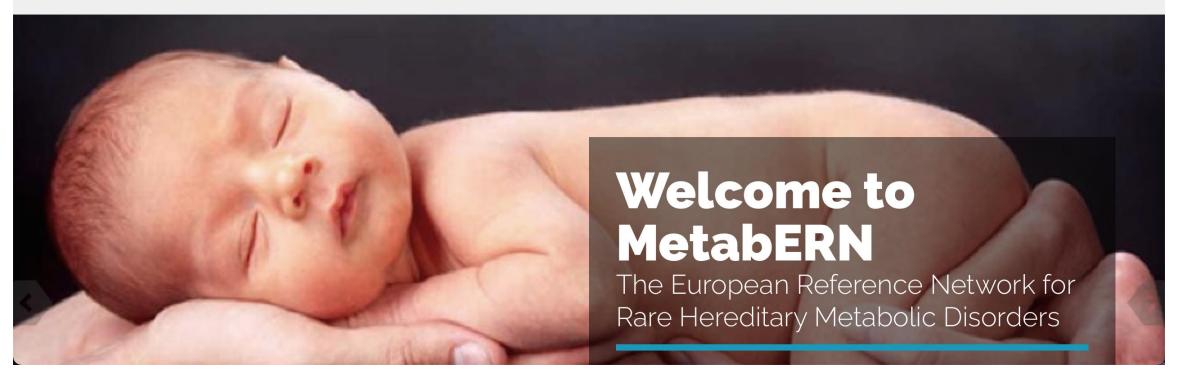
evalence

European Reference Network

MetabERN

European Reference Network for Hereditary Metabolic Disorders

HOME FOR PATIENTS ▼ OUR NETWORK ERN EXPERTISE ▼ MEDIA ▼ WHAT'S NEW ▼ ERNS LINKS CONTACT PRIVACY POLICY



https://metab.ern-net.eu



MetabERN and COVID-19

- METABERN RECOMMENDATIONS FOR ALL RARE INHERITED METABOLIC DISEASES PATIENTS AND CAREGIVERS ABOUT TREATMENT ADHERENCE DURING THE COVID-19 EMERGENCY
- NATIONAL AND DISEASE SPECIFIC RECOMMENDATIONS
- INFOGRAPHIC
- The Clinical Management Support System (COVID19 CMSS)
- COVID-19 vaccination and IMD: MetabERN Recommedation



MetabERN: Hereditary Metabolic Diseases





					complex diseases	
Survey	Open	Closed	N of Q	Responses	Most important Outcomes	
HCPs and Covid-19	29/03/20	17/04/20	30	73 in 21 EU Member States	Most centers reported no cases 24 cases in total 7% of HCP have confirmed pediatric cases (13 cases) 10% of HCP have adult cases (11) Mostly mild or no symptoms No COVID-19-related deaths are known	
					Published in Orphanet Journal of Rare Diseases (Dec. 2020). The impact of COVID-19 on rare metabolic patients and healthcare iders: results from two MetabERN surveys	
Patients and Covid-19	26/03/20	14/04/20	32	39 in 18 EU Member States	Authors: Christina Lampe; Cinzia Bellettato; Laura Paneghetti; Corine vai Lingen; Simon Bond; Colin Brown; Alan Finglas; Rita Francisco; Sylvia Sestini; Jean Michel Heard; Maurizio Scarpa, MetabERN collaboration group	
					replacement for many of the face-to-face meetings is encouraged.	
HCPs and	7/06/202	15/09/202	21	64 in 22	To be analysed	
Covid-19 2° round Survey	0	0			Second paper on prevalences of infection / disease expression / complications/management in patients with IMDs compared to the	
HCPs and Covid 19 3° survey	20/03/20 21	29/03/202 1	12	60 in 21 EU Member states	general population.	







Orphanet Journal of Rare Diseases

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Letter to the Editor | Open Access | Published: 03 December 2020

The impact of COVID-19 on rare metabolic patients and healthcare providers: results from two MetabERN surveys

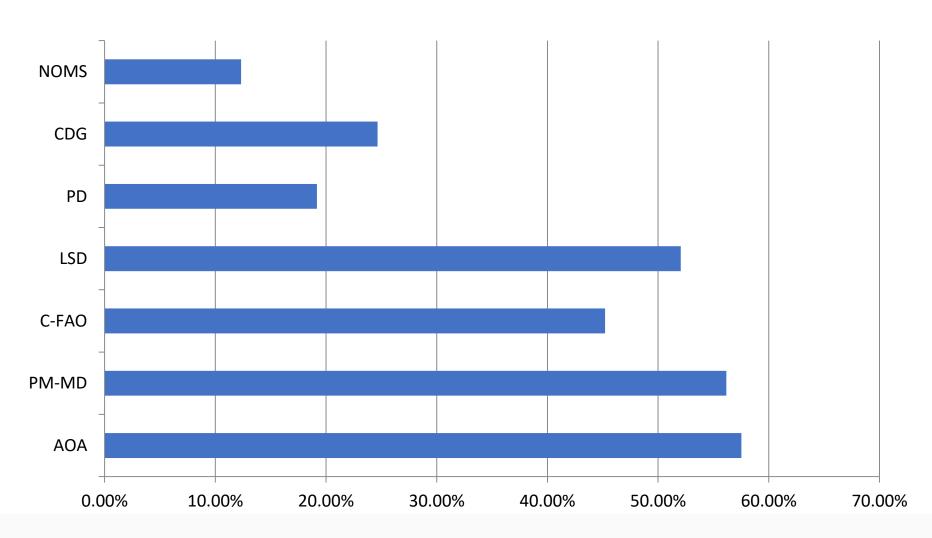
Orphanet Journal of Rare Diseases 15, Article number: 341 (2020) Cite this article

1974 Accesses | 1 Citations | 12 Altmetric | Metrics



Disease categories considered at major risk for severe COVID-19

(% of centers considering the disease at major risk)





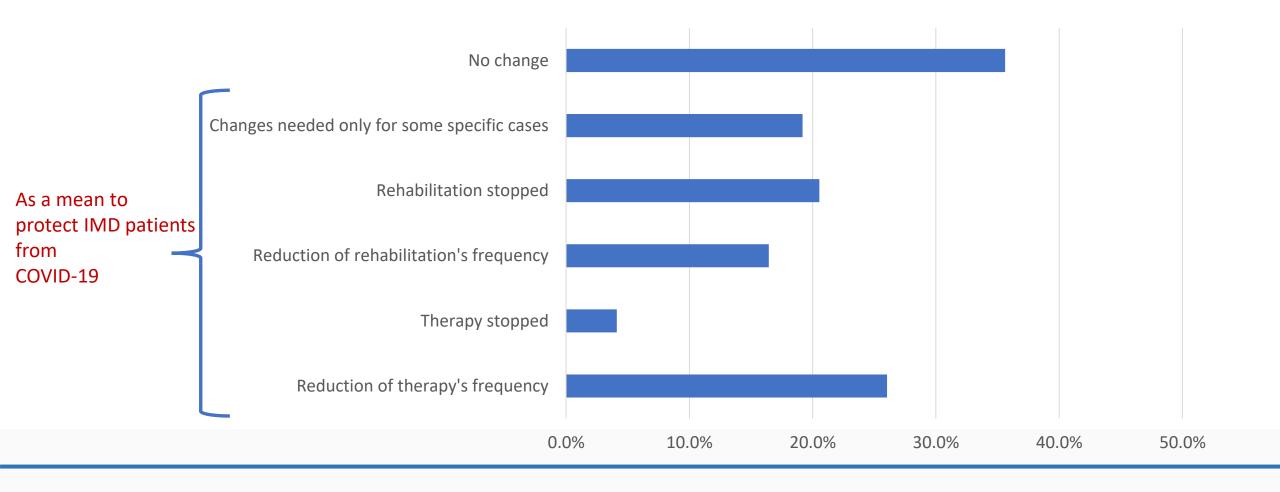
Management of rare metabolic patients during the emergency

90% of MetabERN centers had to change the management of their patients due to the ongoing pandemic.



Changes in IMD patients' therapy regimen at the beginning of the COVID-19 emergency

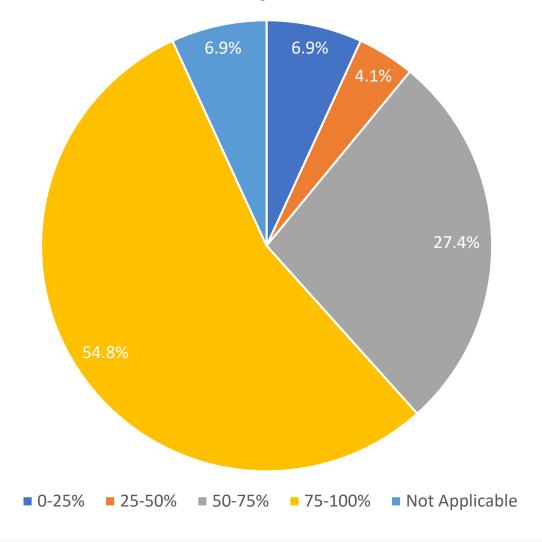
(% of centers; more than one answer possible)





· Network

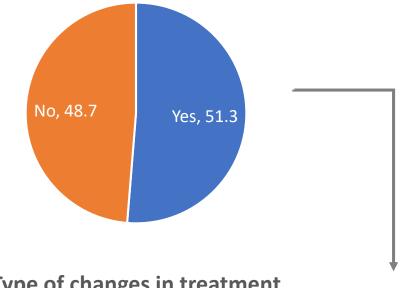
Proportion of missed outpatient visits at the centre



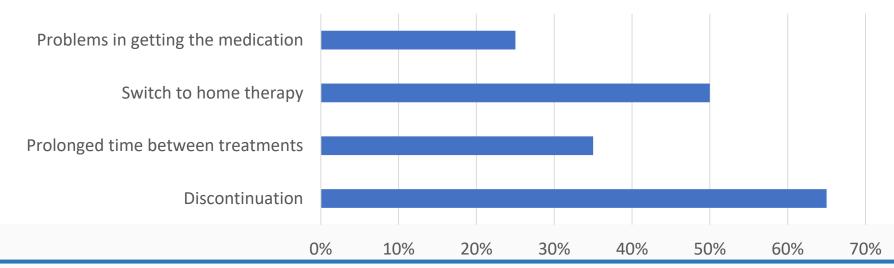
Change in treatment due to COVID-19 emergency



· Network Hereditary Metabolic Disorders (MetabERN)



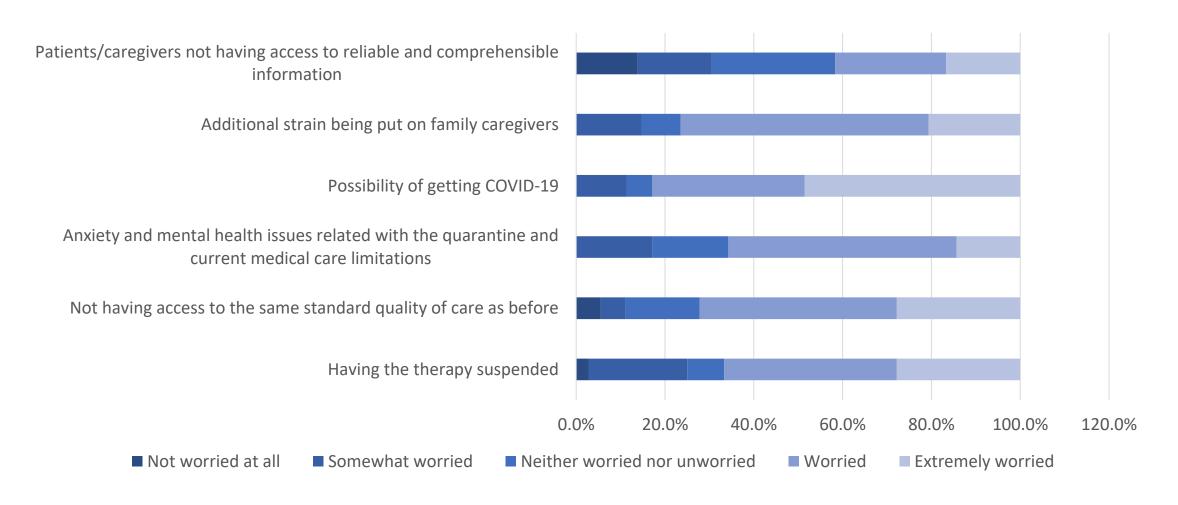
Type of changes in treatment





Type and level of concern of the IMD patient community represented by the PO

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COVID-19 Survey 3

Reference Network for rare or low prevalence complex diseases

Hereditary Metabolic Disorders (MetabERN)

· Network

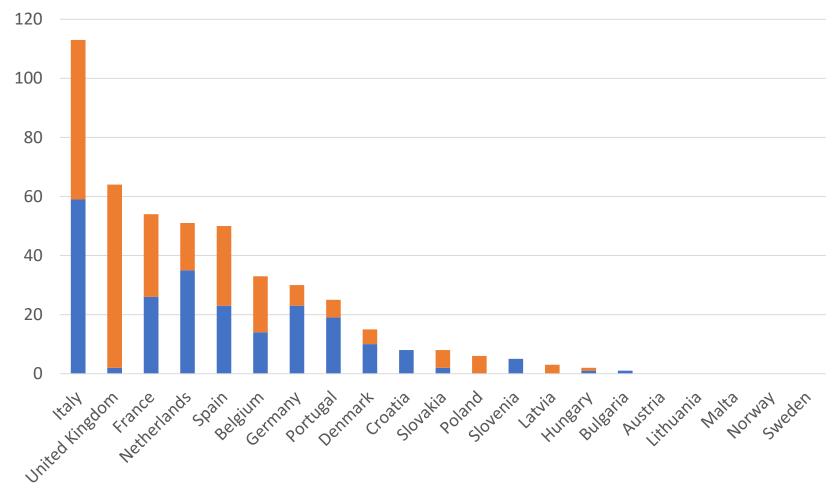
Reported cases of COVID-19 among IMD patients followed by MetabERN since the beginning of the pandemic

Country	Paediatric	Adult	TOT
Austria	0	0	0
Belgium	14	19	33
Bulgaria	1	0	1
Germany	23	7	30
Denmark	10	5	15
Spain	23	27	50
France	26	28	54
Croatia	8	0	8
Hungary	1	1	2
Italy	59	54	113
Lithuania	0	0	0
Latvia	0	3	3
Malta	0	0	0
Netherlands	35	16	51
Norway	0	0	0
United Kingdom	2	62	64
Poland	0	6	6
Portugal	19	6	25
Sweden	0	0	0
Slovenia	5	0	5
Slovakia	2	6	8
	228	240	468

Crude preliminary data that requires further analysis



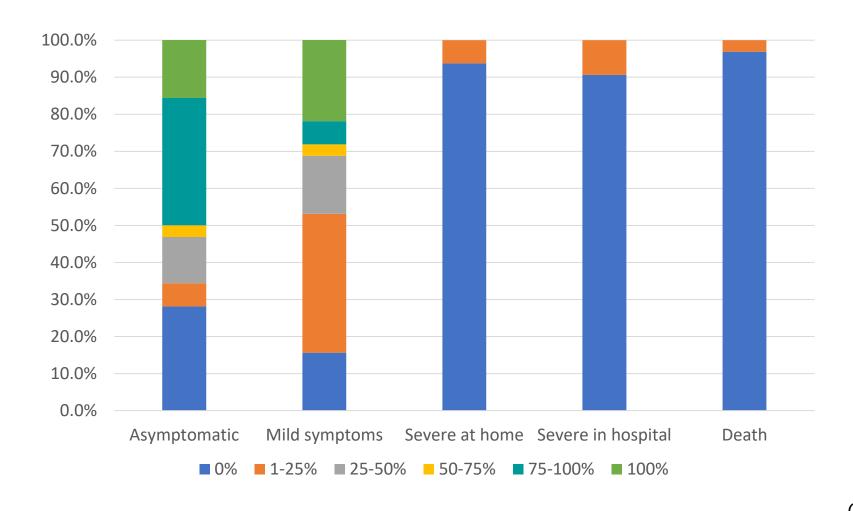
National distribution of reported cases of COVID-19 among IMD patients followed by MetabERN since the beginning of the pandemic



■ Paediatric ■ Adult



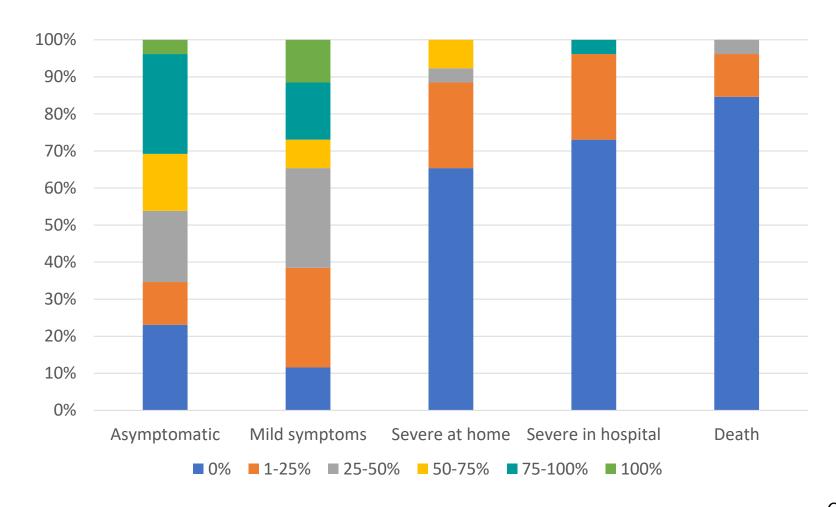
Severity of COVID-19 symptoms in paediatric cases



Crude preliminary data that requires further analysis



Severity of COVID-19 symptoms in adult cases



Crude preliminary data that requires further analysis



Conclusion

Rare metabolic patients need to be protected not only from the risk of coronavirus infection, but also from the possible degeneration of their disease.

To this end, a network of HCPs in close contact with IMD patients and their caregivers is essential to provide patients with the necessary support and care

During the initial phase of the coronavirus pandemic, the highly medically supervised **population of IMD patients was relatively protected from the infection (MetabERN Recommendations).**

This was made possible also by the widespread use of telemedicine in the metabolic community and home therapy.

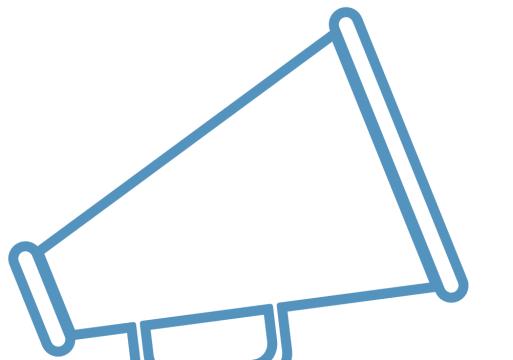
The data from our second survey seem to confirm the trend of the first survey with patients mostly showing mild symptoms of the Covid-19 disease

More time is needed to determine the actual consequences of the COVID-19 emergency on IMD patients



'Un Amico Raro'

COMMUNICATION PARTNERSHIP



- Regular posts for dissemination through MetabERN's social media channels
- Dedicated presentation of today's event in the news section of MetabERN's website
- Presentation of the project to be disseminated on April's newsletter