

**GIOVEDÌ 22 APRILE 2021 dalle 11.00 alle 13.00**

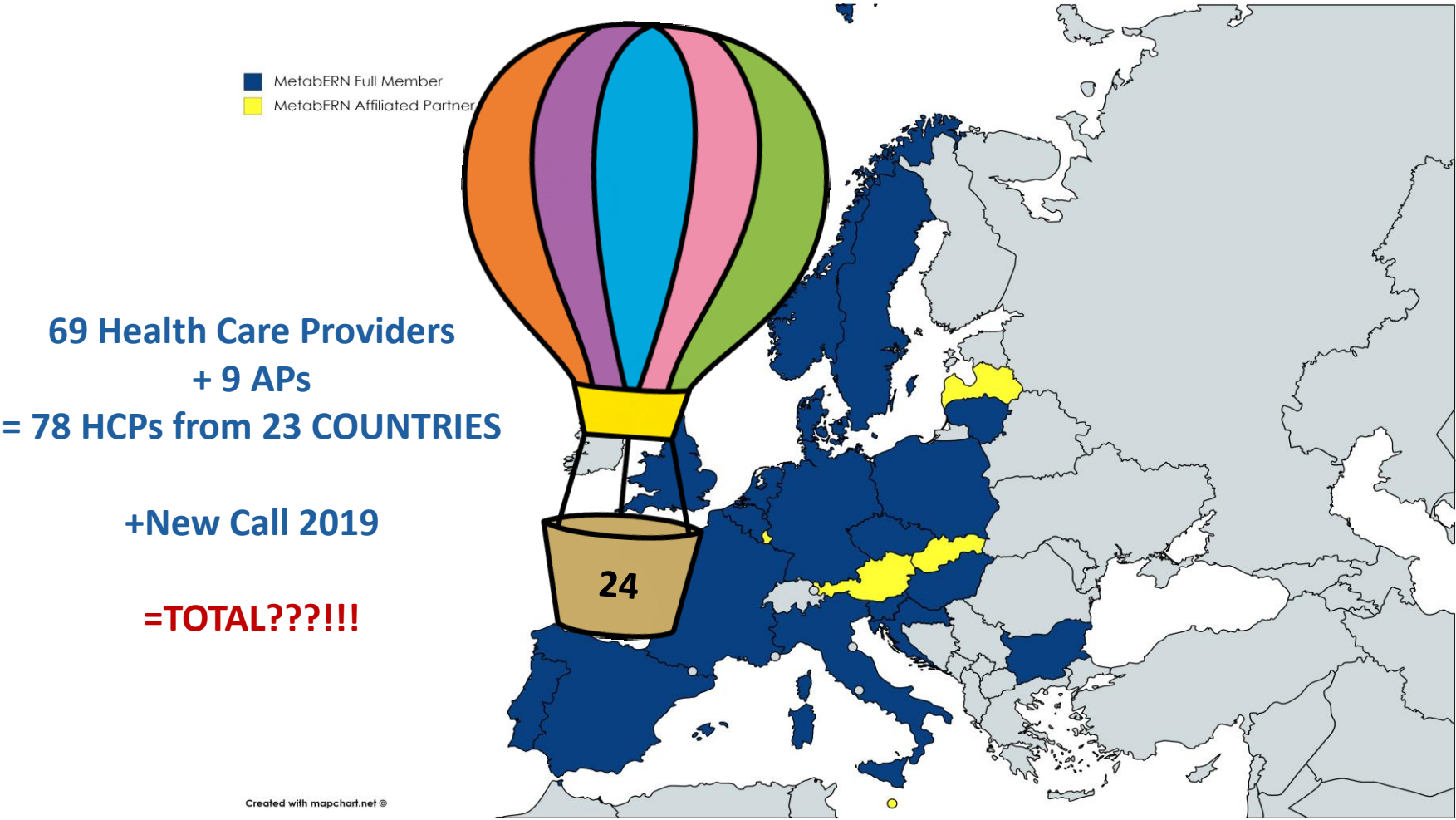
EVENTO DEDICATO ALLA MALATTIA DI ANDERSON-FABRY e  
PRESENTAZIONE DEL CARTONE ANIMATO



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

*Relatrice: Dott.ssa Cinzia Maria Bellettato – MetabERN*

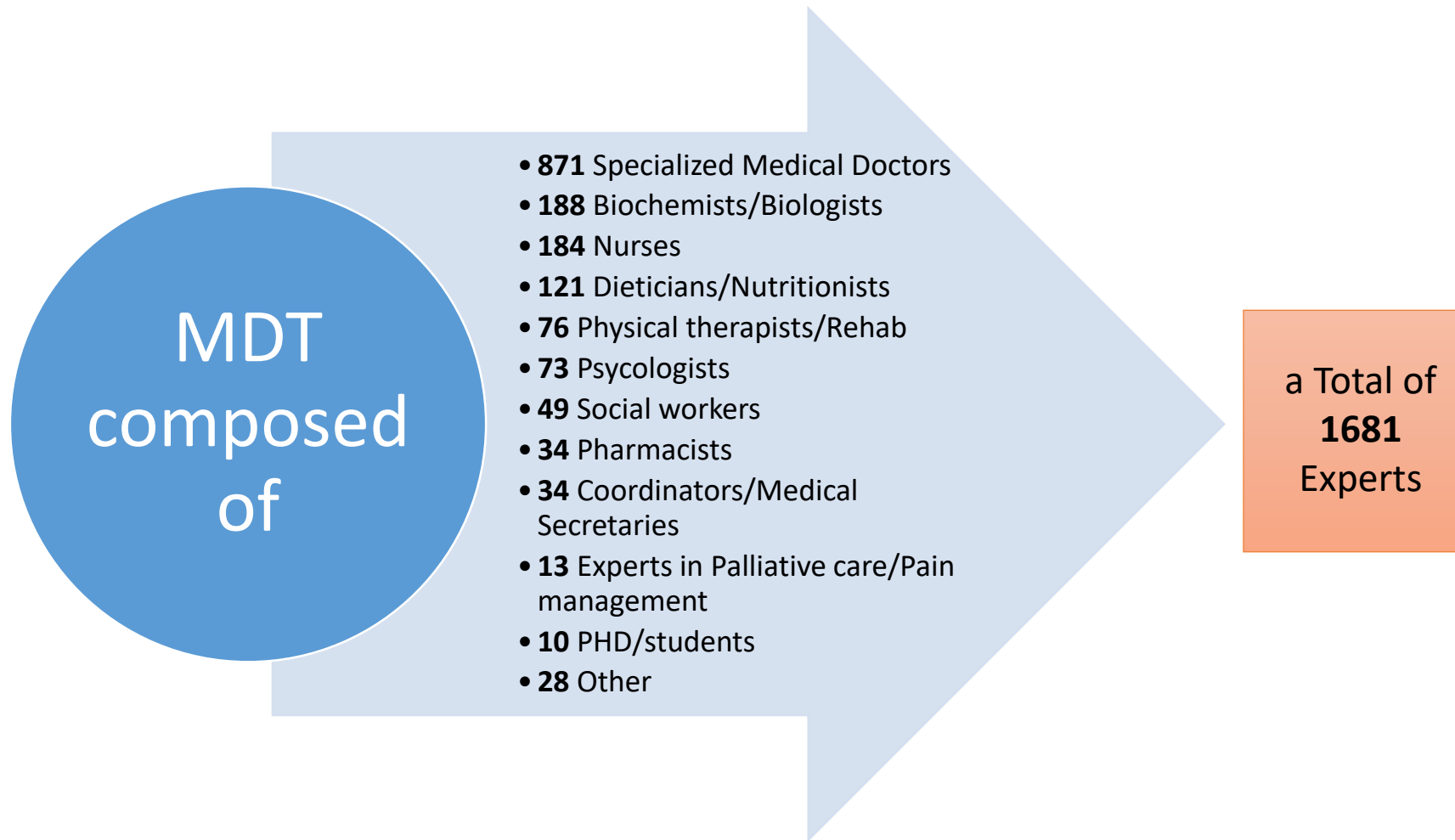
# MetabERN Geographic Coverage



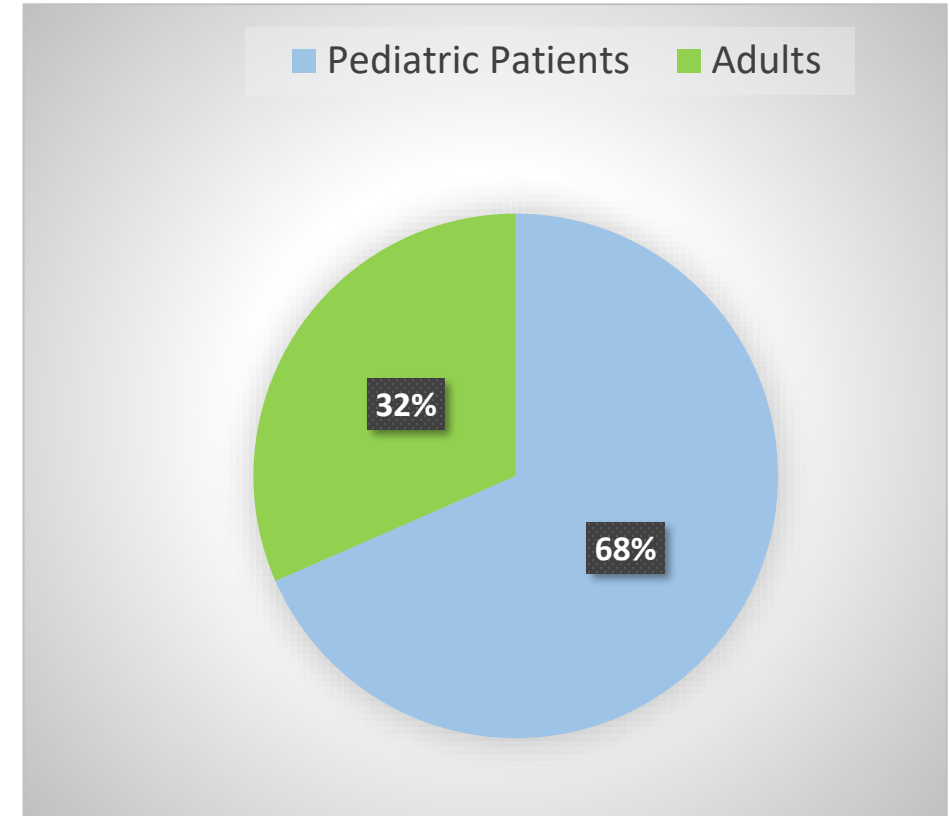
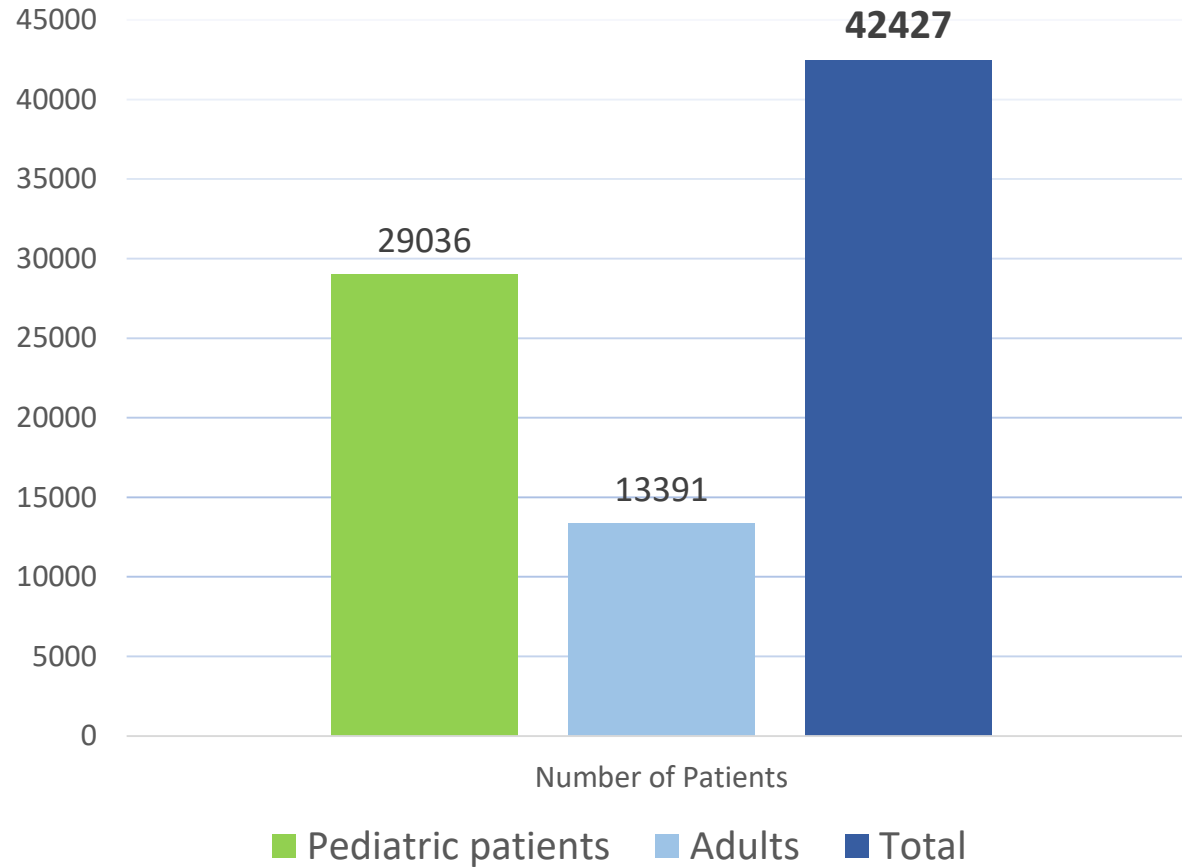
78 Health Care Providers from 23 COUNTRIES

AU	BE	BG	CZ	DE	DK	ES	FR	HR	HU	IT	LT	LV	LX	MT	NL	NO	PL	PT	SE	SI	SK	UK
4	6	1	1	10	1	5	9	1	1	11	1	1	2	1	5	2	1	5	2	1	1	6

## METABERN MULTIDISCIPLINARY TEAM (MDT)



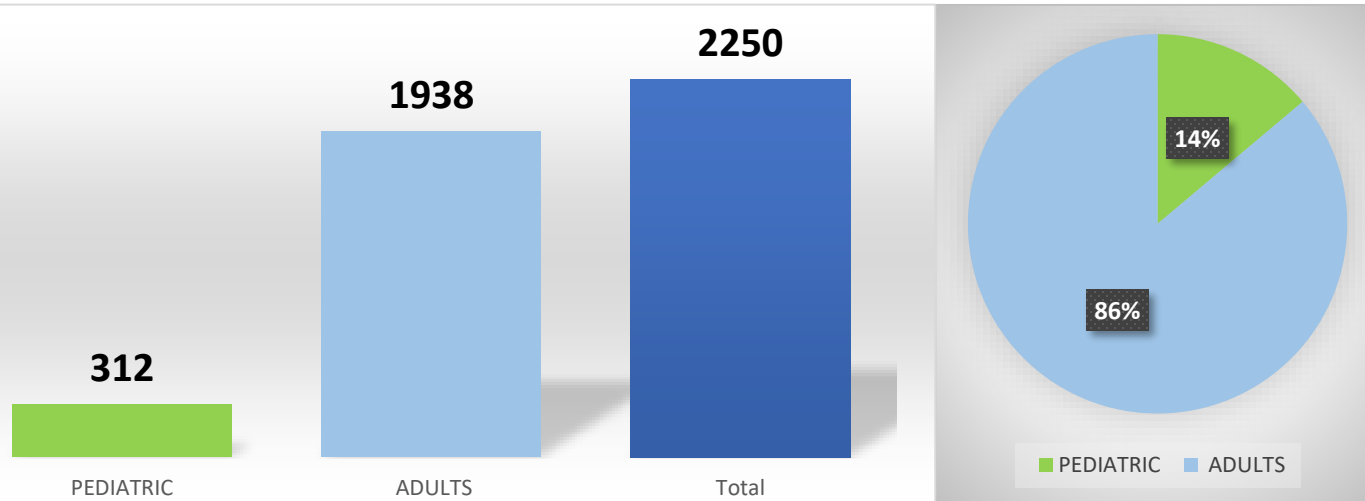
## MetabERN: Patients Coverage



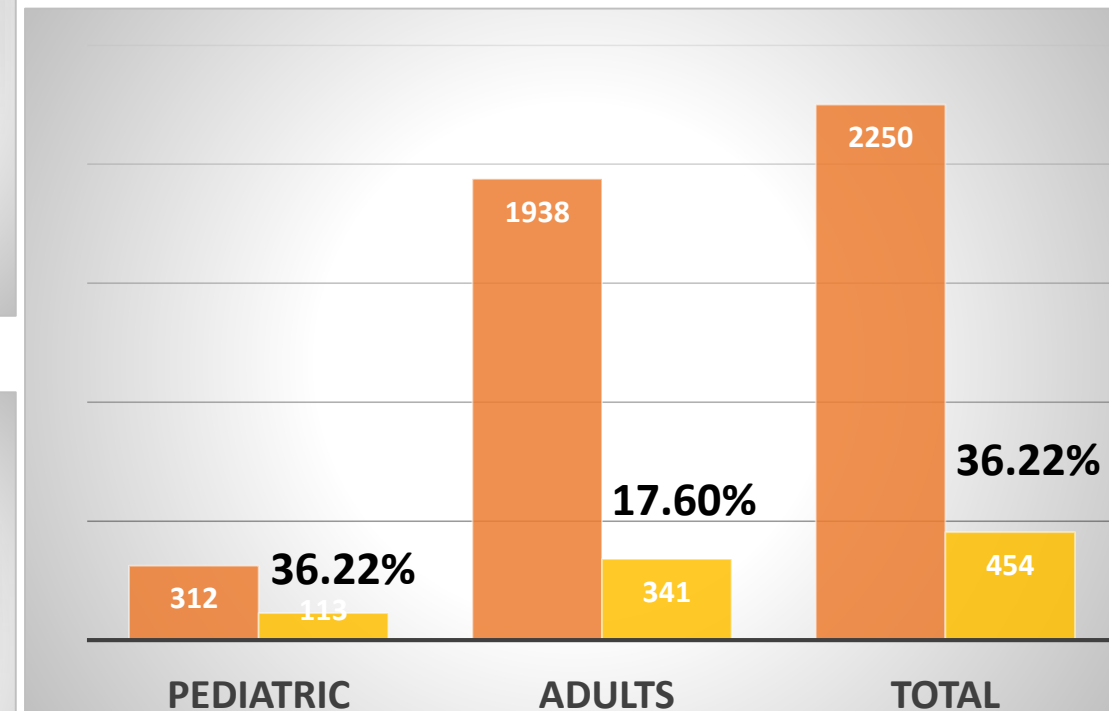
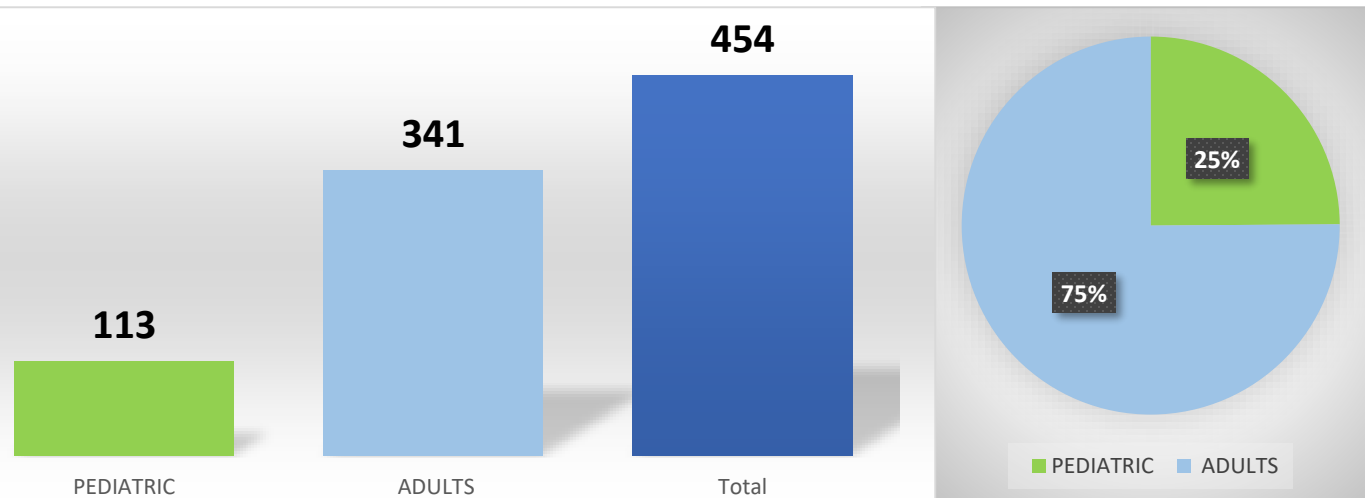
*Data from MetabERN Full  
member applications 2017*

# Patients with Fabry followed by MetabERN

## Total Patients



## Italian Patients

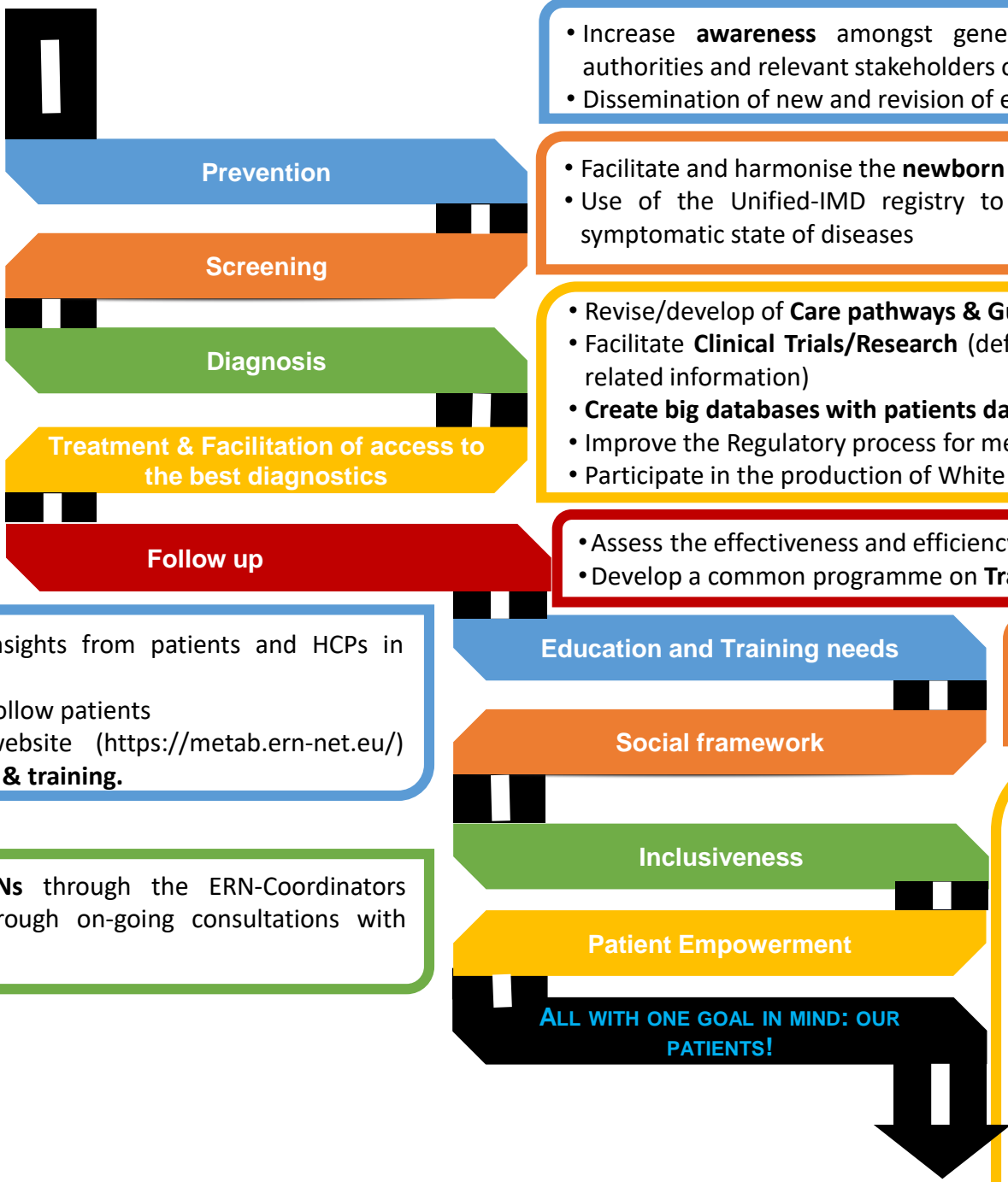


**MetabERN:**  
**How we share, how we care**

- 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

- Participate in and provide input and insights from patients and HCPs in **Education of patients**
- **Instruct general practitioners** 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)







European  
Reference  
Network

MetabERN

European Reference Network  
for Hereditary Metabolic Disorders

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**Welcome to  
MetabERN**

The European Reference Network for  
Rare Hereditary Metabolic Disorders

<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 Recommendation](#)

[www.metab.ern-net.eu](http://www.metab.ern-net.eu)





# The impact of COVID-19 on rare metabolic patients and HCPs

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	<p><b>Most centers reported no cases</b>  24 cases in total  7% of HCP have confirmed <b>pediatric cases (13 cases)</b>  10% of HCP have <b>adult cases (11)</b>  <b>Mostly mild or no symptoms</b>  <b>No COVID-19-related deaths</b> are known</p> <p><b>Data Published in Orphanet Journal of Rare Diseases (Dec. 2020).</b>  <b>Title:</b> The impact of COVID-19 on rare metabolic patients and healthcare providers: results from two MetabERN surveys  <b>Authors:</b> <i>Christina Lampe; Cinzia Bellettato; Laura Paneghetti; Corine van Lingen; Simon Bond; Colin Brown; Alan Finglas; Rita Francisco; Sylvia Sestini; Jean Michel Heard; Maurizio Scarpa, MetabERN collaboration group</i></p>
Patients and Covid-19	26/03/20	14/04/20	32	39 in 18 EU Member States	<p><i>replacement for many of the face-to-face meetings is encouraged.</i></p>
HCPs and Covid-19 2° round Survey	7/06/2020	15/09/2020	21	64 in 22	<p><b>To be analysed</b></p> <p><b>Second paper on</b> prevalences of infection / disease expression / complications/management in patients with IMDs compared to the general population.</p>
HCPs and Covid 19 3° survey	20/03/2021	29/03/2021	12	60 in 21 EU Member states	

 **BMC** Part of Springer Nature

 **Orphanet Journal of Rare Diseases**

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

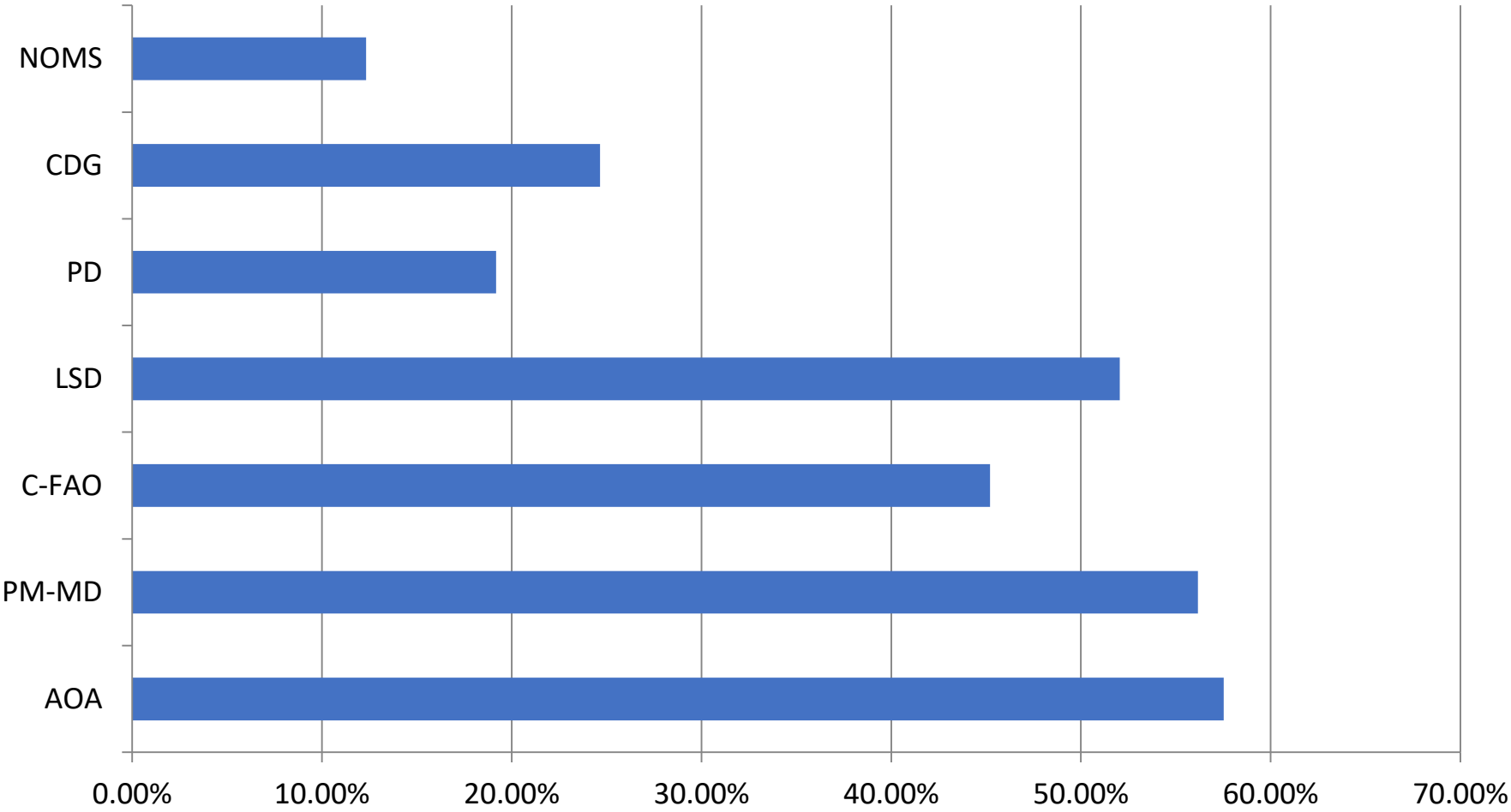
[C. Lampe](#), [C. Dionisi-Vici](#), [C. M. Bellettato](#), [L. Paneghetti](#), [C. van Lingen](#), [S. Bond](#), [C. Brown](#), [A. Finglas](#), [R. Francisco](#), [S. Sestini](#), [J. M. Heard](#), [M. Scarpa](#)  & [MetabERN collaboration group](#)

[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)

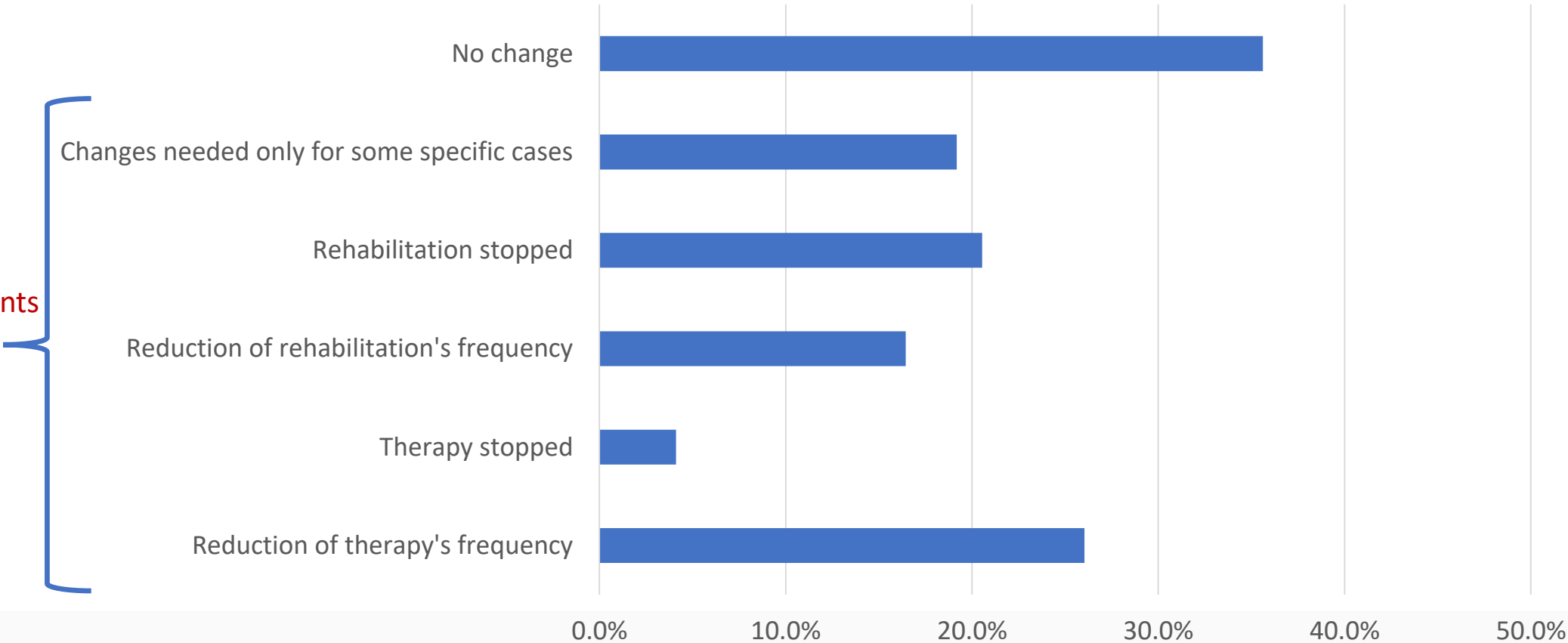


## Management of rare metabolic patients during the emergency

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

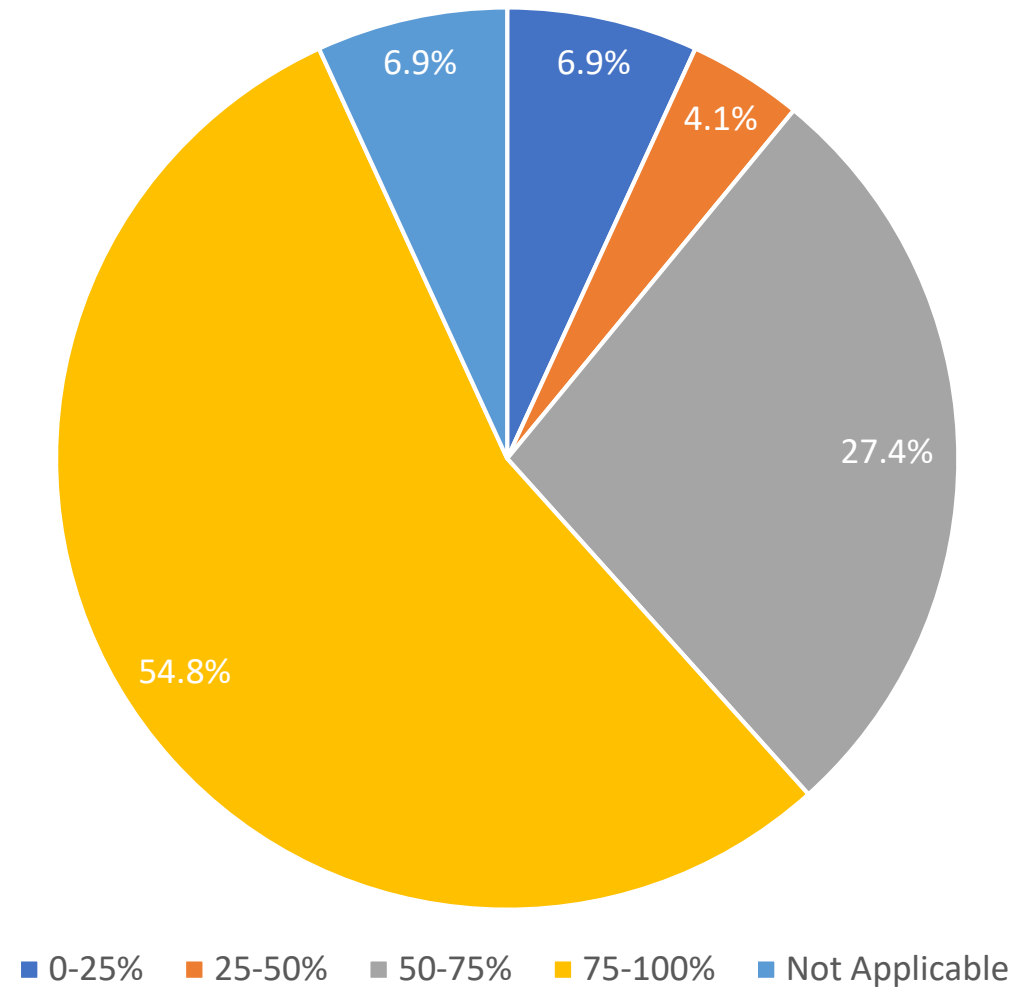
**Changes in IMD patients' therapy regimen  
at the beginning of the COVID-19 emergency  
(% of centers; more than one answer possible)**

As a mean to  
protect IMD patients  
from  
COVID-19

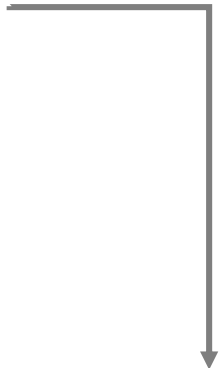
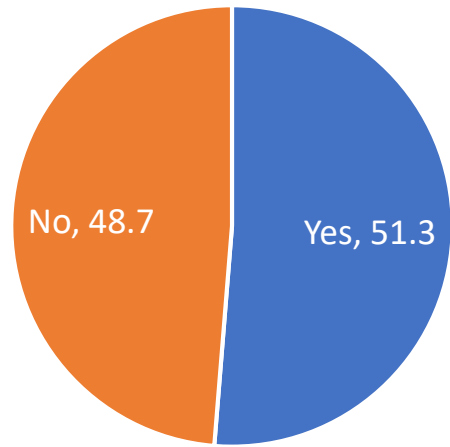




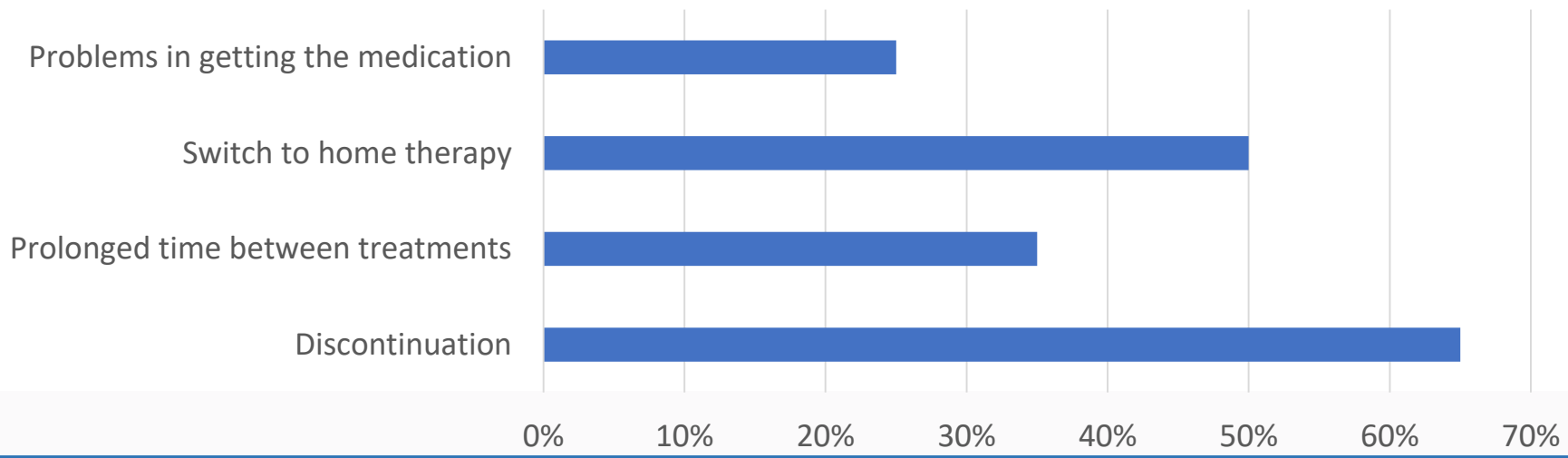
# Proportion of missed outpatient visits at the centre



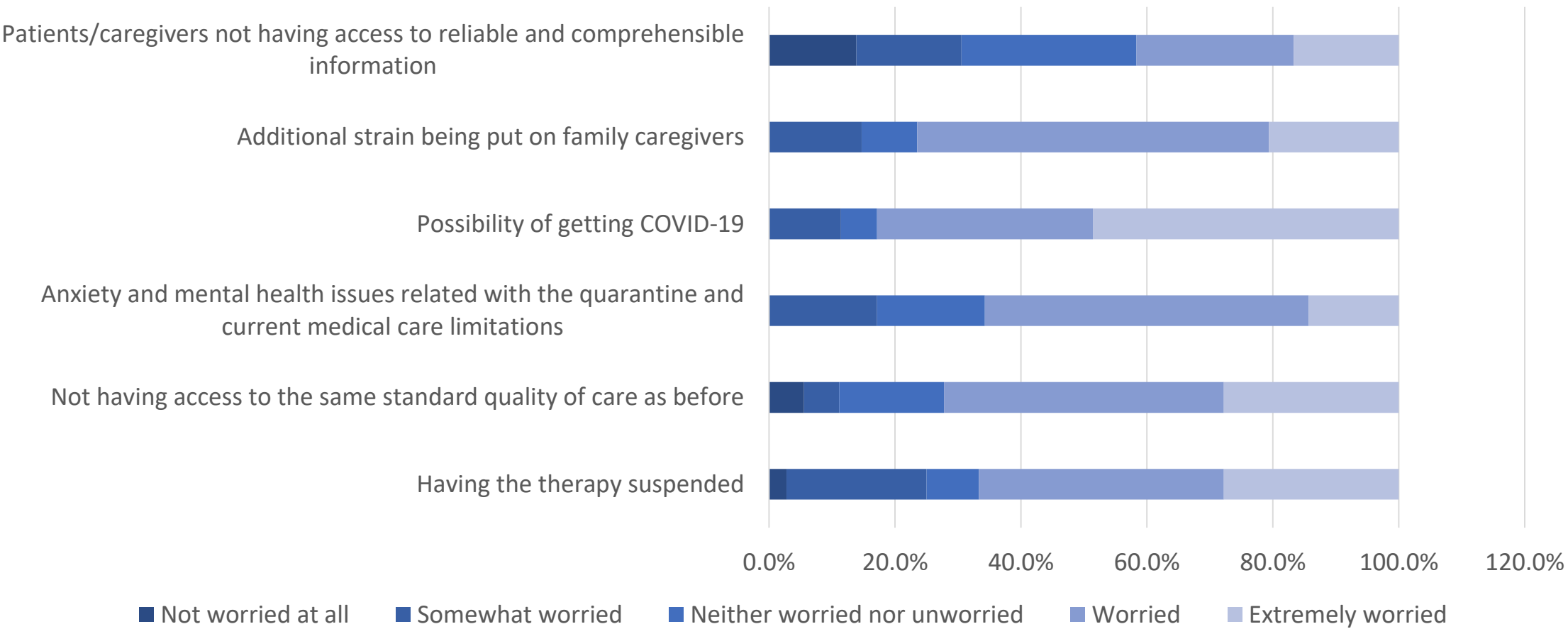
# Change in treatment due to COVID-19 emergency



## Type of changes in treatment



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



# COVID-19 Survey 3

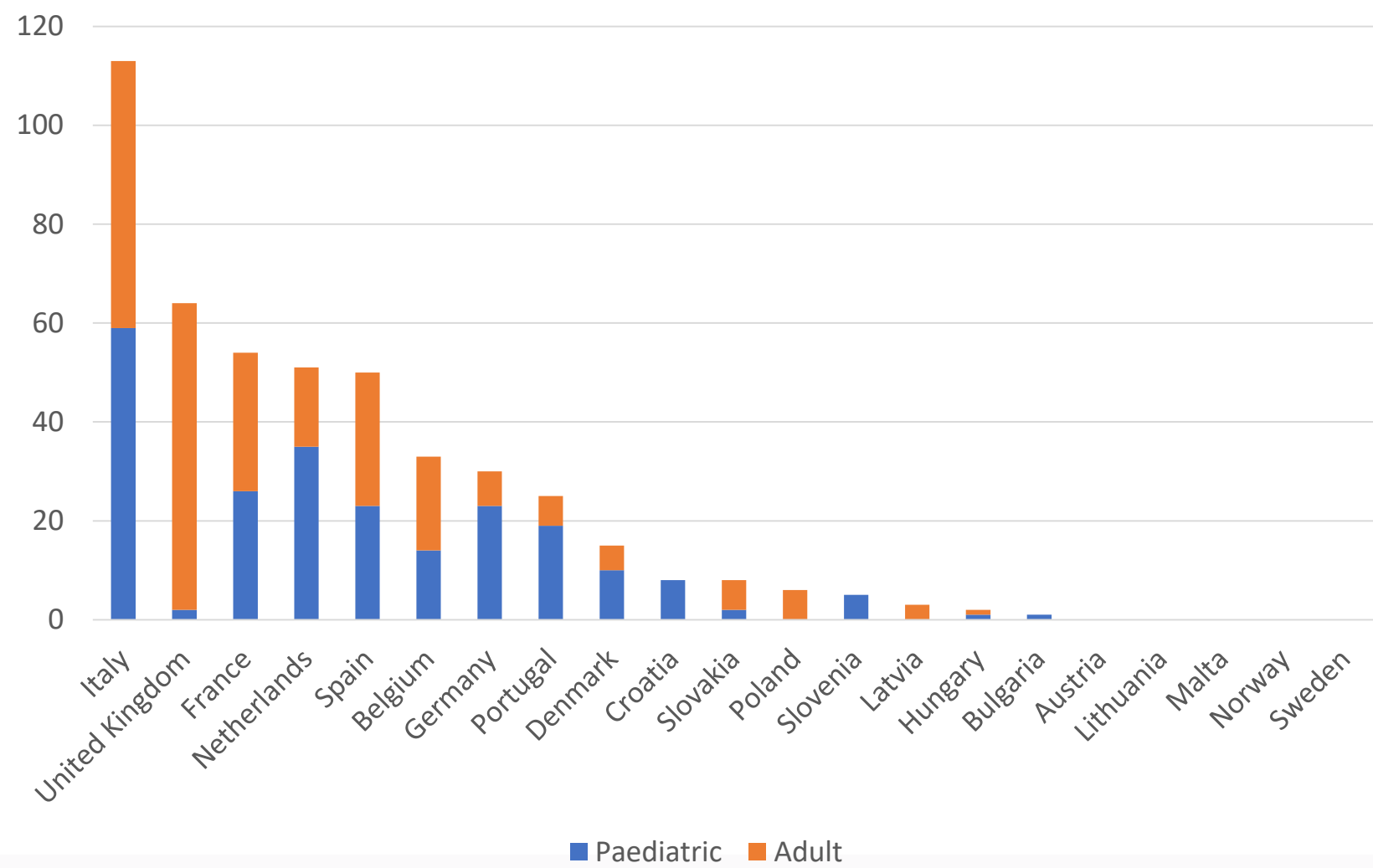
**Reported cases of COVID-19 among IMD patients  
followed by MetabERN since the beginning of the pandemic**

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*

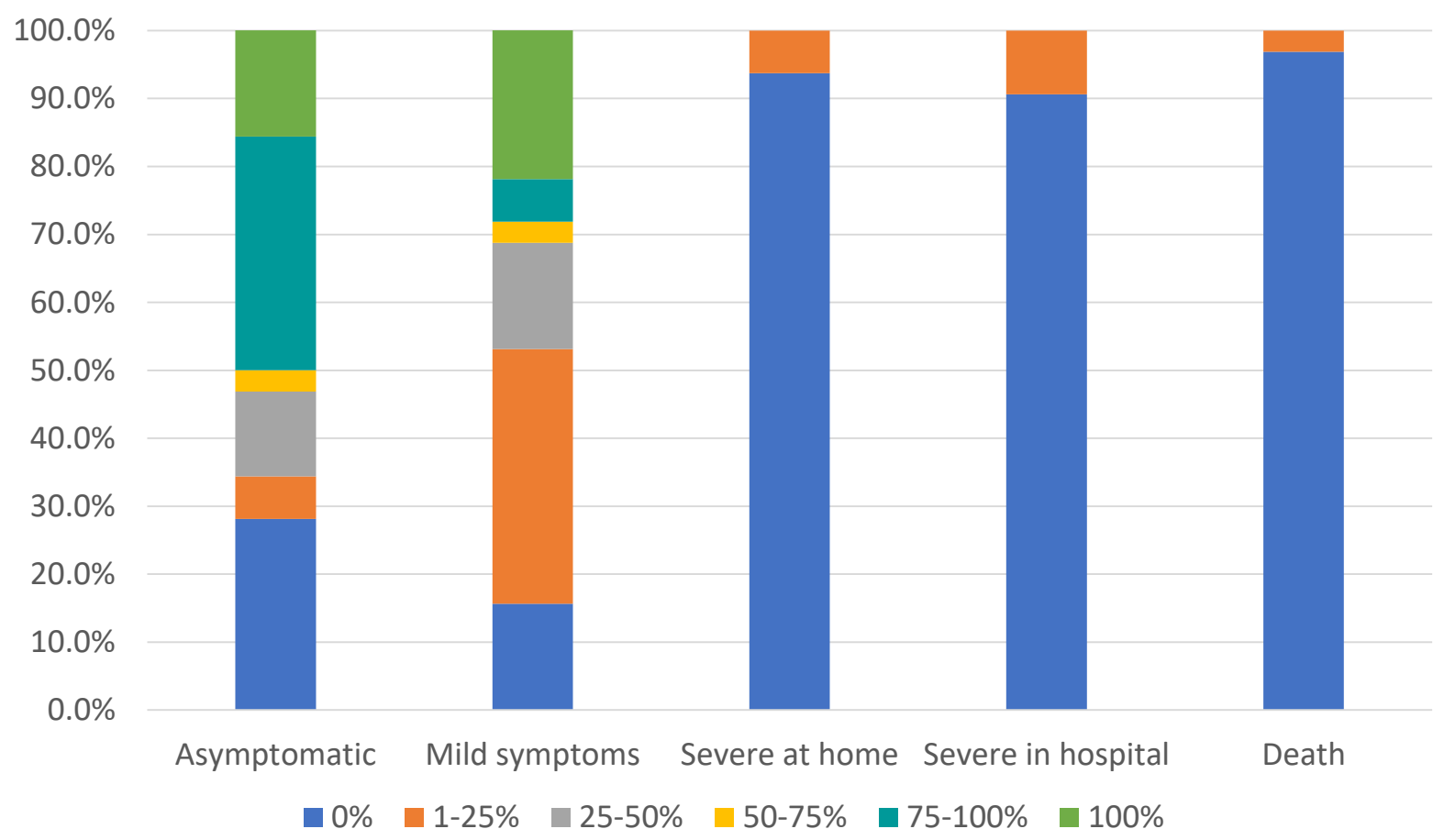


# National distribution of reported cases of COVID-19 among IMD patients followed by MetabERN since the beginning of the pandemic



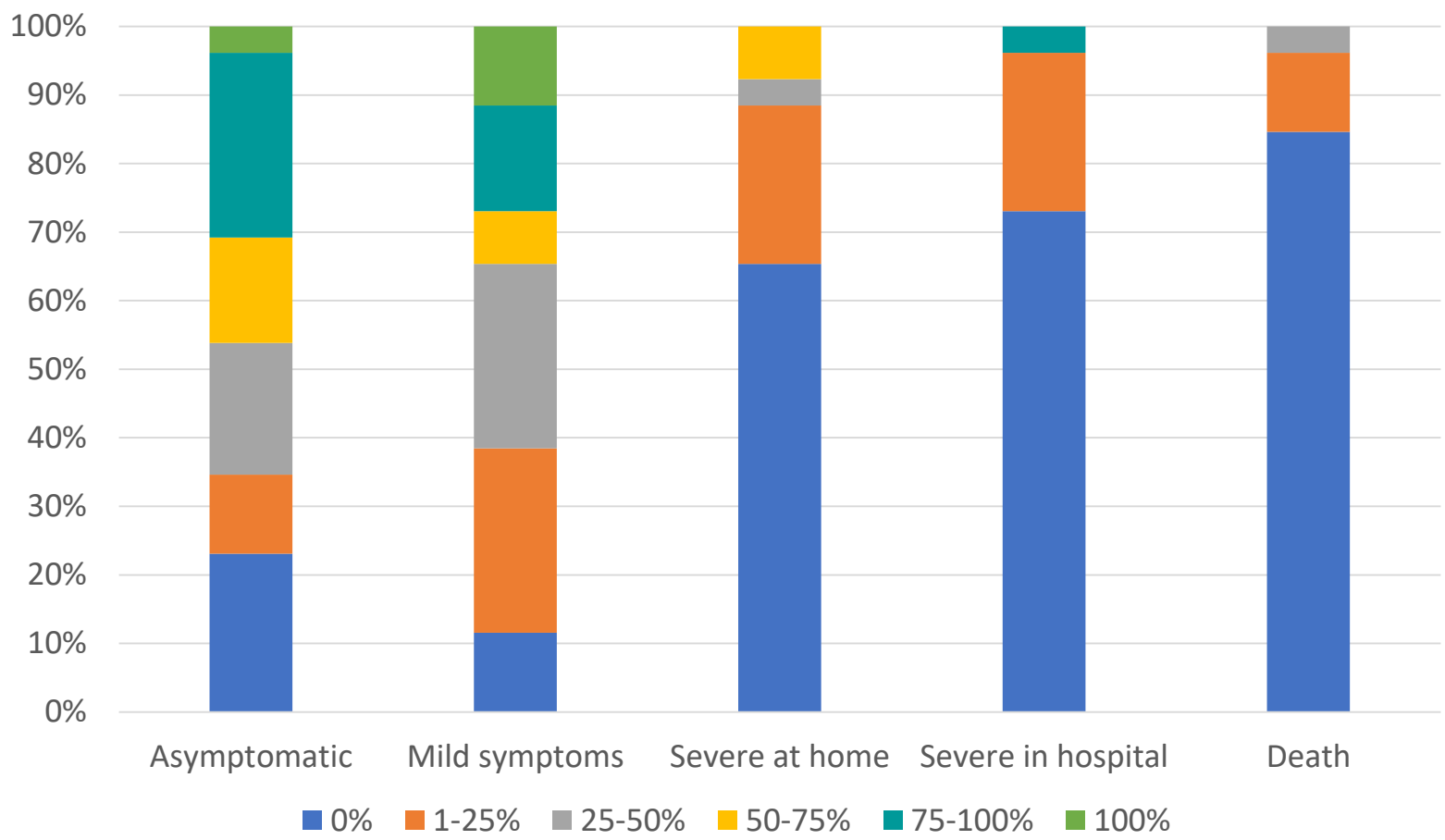
*Crude preliminary data that  
requires further analysis*

# 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



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'Un Amico Raro'

# COMMUNICATION PARTNERSHIP

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- 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**

