

Supplemental Figure 1

Survey on the use of telemedicine in NMD in Europe during COVID-19 pandemic

For

Medical Doctors

Since the COVID-19 pandemic, telemedicine has been used widely in Europe and has benefited a large number of patients, but little is known about the overall development of telemedicine in the field of Neuromuscular Disease (NMD) in Europe.

Therefore, we elaborated a survey that will allow us collect data on the use of telemedicine in the field of NMD in Europe in the context of COVID-19 pandemic.

Directions:

1. Please read carefully the definition of telemedicine (page 2)
2. Please write down the date and your initials (begin with the letter of your last name)
3. Please answer the questions of the survey (pages 3-10).

Thank you for taking part in our survey!

Definition of Telemedicine

Telemedicine (TM) is a clinical application connecting a patient with specialized care clinicians by means of an electronic platform, potentially able to improve patients' self-management and allow for the care of patients with limited access to health services.

Telemedicine is declined in five acts (DGOS, 2012¹) that are listed below:

- Tele-consultation (allows a medical professional to consult a patient remotely via Communication Technologies for the purpose of providing diagnostic or therapeutic advice).
- Tele-expertise (practice in which a physician benefits from professional advices provided by other physicians via Information and Communication Technologies to improve a patient's clinical health status). It can be achieved outside the presence of the patient.
- Tele-monitoring (allows a medical professional to monitor and supervise a patient remotely via ICTs).
- Tele-assistance (it allows a medical professional to assist remotely another medical professional during an intervention via ICTs).
- Medical Response (used to provide quick and efficient emergency services. The paramedics support the medical response of both air and ground ambulances).

¹ Technical Working Group/Information Systems, French Ministry of Employment, Labour and Health. Recommendations for the implementation of a telemedicine project, Technical Deployment: Urbanization and infrastructure, March 2012.

Please fill out the date and your initials

Date:

Initials:

Thank you for answering the following questions (pages 3-13)

■ **Hospital/Clinical name** (please specify the country where you work):

- Name: _____
- Country: _____
- How long have you been working as HCPs?
_____year(s)

■ **Please specify your main area of interest in NMD** (multiple options are possible):

Muscle

- Nerve
- Motorneuron
- Neuromuscular junction
- Mitochondria

■ **Please specify the total number of patients annually seen in your subspecialty (ies):**

- 0-50 _____
- 50-200 _____
- 200-400 _____
- 400-800 _____
- >800 _____
- Other, please specify _____
- I don't know _____

BEFORE COVID-19 PANDEMIC

■ **Have you ever used telemedicine (TM) before COVID-19 pandemic?**

- Yes
 No

If yes, please specify the types of telemedicine used (multiple options possible)

- | | |
|--|--|
| <input type="checkbox"/> Teleconsultation | <input type="checkbox"/> Tele-assistance |
| <input type="checkbox"/> Consultation by phone | <input type="checkbox"/> Tele-expertise |
| <input type="checkbox"/> Tele-monitoring | <input type="checkbox"/> Medical Responses |

Please specify the percentage and age category of patients for the different types of telemedicine (Total has to be 100%):

In case of teleconsultations:

- _____ % < 14
- _____ % 14-18
- _____ % 18-30
- _____ % 30-40
- _____ % 40-60
- _____ % > 60

In case of consultations by phone:

- _____ % < 14
- _____ % 14-18
- _____ % 18-30
- _____ % 30-40
- _____ % 40-60
- _____ % > 60

In case of tele-monitoring:

- _____ % < 14
- _____ % 14-18
- _____ % 18-30
- _____ % 30-40
- _____ % 40-60
- _____ % > 60

- **In which context have you used TM?** (possibility to tick multiple boxes and for each box, please specify the type of TM used)

For example: Patient diagnosis: [teleconsultation & consultation by phone](#)_

- Patient diagnosis: _____
- Therapy, therapeutic trial, home therapy: _____
- Advices for Physical therapy: _____
- Psychotherapy: _____
- Patients general follow-up: _____
- Other, specify: _____

- **How valuable is TM for the care of NMD patients in your institution**

- | | |
|-------------------------------------|---|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> Very important |
| <input type="checkbox"/> Somehow | <input type="checkbox"/> Essential |
| <input type="checkbox"/> Important | <input type="checkbox"/> don't have any opinion |

- **Please specify if teleconsultation is covered by healthcare insurance in your institution/country**

- Yes
 No
 don't know

DURING COVID-19 PANDEMIC

■ **Have you ever used TM during COVID-19 pandemic?**

Yes

No

If yes, please specify the types of telemedicine used

Teleconsultation

Tele-assistance

Consultation by phone

Tele-expertise

Tele-monitoring

Medical Responses

If yes, please specify the percentage and age category of patients
(Total has to be 100%):

In case of teleconsultations:

- _____ % <14
- _____ % 14-18
- _____ % 18-30
- _____ % 30-40
- _____ % 40-60
- _____ % >60

In case of consultations by phone:

- _____ % < 14
- _____ % 14-18
- _____ % 18-30

- _____ % 30-40
- _____ % 40-60
- _____ % > 60

In case of tele-monitoring:

- _____ % < 14
- _____ % 14-18
- _____ % 18-30
- _____ % 30-40
- _____ % 40-60
- _____ % > 60

- **In which context have you used TM?** (possibility to tick multiple boxes and for each choice, please specify the type of TM used i.e teleconsultation, telemonitoring or consultation by phone)

- Diagnosis _____
- Therapy _____
- Clinical trial _____
- Home therapy _____
- Referral for physical therapy _____
- If appropriate (in case of mental health issues) referral to psychiatrist/psychologist or social worker _____
- Patients' general follow-up _____
- Worsening of NMD disease with COVID-19 infection _____
- Other, specify _____

- **What percentage of NMD patients have you seen in TM for diagnosis, treatment or other management issues due to COVID-19?** For each choice, please specify the type of TM used

- 1 to 25% _____
- 25 to 50% _____
- 50 to 75% _____
- 75 to 100% _____
- Other, please specify _____
- I don't know _____

■ **How valuable is TM for the care of NMD patients during COVID-19 pandemic?**

- Not at all
- Somehow
- Important
- Very important
- Essential
- I don't have any opinion

■ **Please specify if teleconsultation is covered by healthcare insurance in your institution/country**

- Yes
- No
- I don't know

■ **If you have used teleconsultation or telemonitoring on a regular basis with your patients (before or during COVID-19 pandemic), please answer the following questions:**

TECHNICAL FEASIBILITY:

- Was the delay of the connection to TM platform acceptable?

YES	NO
-----	----

- Were there any bugs that prevented the progress of teleconsultation?

YES	NO
-----	----

- Was the image quality acceptable?

YES	NO
-----	----

- Was the sound quality acceptable?

YES	NO
-----	----

- Was the data transmission acceptable?

YES	NO
-----	----

ACCEPTABILITY:

- I am satisfied with the patients follow up remotely via TM

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Comments :

- **I have adopted this method of care for my patients on a regular basis.**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Comments :

- **If not on a regular basis, I will be happy to repeat this experience.**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
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Comments:

QUALITY OF CARE:

- **Compared to classical care, I felt to be more available for my patients while using TM.**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Comments :

- **Since your last teleconsultation (or last telemonitoring), was there any type of emergency or hospitalization scheduled for your patient?**

YES	NO
-----	----

If yes, how many times:

Consultation: _____

Unscheduled hospitalization: _____

Admission to the emergency room: _____

- **Teleconsultation or telemonitoring allowed me to take care of my patient in an appropriate way.**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Comments :

- **TM has a positive impact on patient care. Do you agree?**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Comments :

ACCESSIBILITY:

- **Compared to routine/classical care, teleconsultation/telemonitoring is more convenient in terms of scheduling an appointment**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Comments :

- **Compared to routine/classical care, teleconsultation/telemonitoring is more convenient in terms of workspace dedicated to consultation.**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
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Comments :

- **Compared to routine/classical care, teleconsultation/telemonitoring allows me to be on time for the teleconsultations.**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Comments :

GLOBAL APPRECIATION:

- **I am generally satisfied with TM experience**

Completely disagree

completely agree

1	2	3	4	5	6	7	8	9	10
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Comments

■ Please specify below what was the unmet need while using TM

Comments :

Thank you for your valuable participation to this survey!



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Neuromuscular
Diseases (ERN EURO-NMD)