Privacy Policy - Duchenne Map

version 2.0

01/06/2022

Contents

1. Identification and contact details of Data Controller

1.1 Who we are

Welcome to the Duchenne Map, a Platform as a Service (PaaS) (hereafter: "the "**Duchenne Map**") operated by **Stichting Duchenne Data Foundation** (hereinafter '**DDF'** or '**We**'), with Chamber of Commerce Registration Number no: 64601188 and principal address at Warmoesdreef 10, 4614 HC, Bergen op Zoom, the Netherlands.

1.2 Our responsibilities

DDF is the data controller and processor (hereinafter, the "Data Controller" and the "Data Processor") responsible for identifying the purpose and the means of the processing of your personal (health) data in relation with Duchenne Map. DDF will process your personal (health) data for allowing registration and use of Duchenne Map, being the legal basis for this processing, the contractual relationship (disregarding the gratuity of the service) and your consent, when processing health-related data.

We will not share your data with third parties; however, it may be accessed by our service providers where such access is necessary for the provision of the service. You have the right to access, rectify and erase your data, and other rights, as indicated in the Privacy Policy.

1.3 About this Privacy Policy

This Privacy Policy is effective as of 1 June 2022 and will remain in effect except with respect to any changes in its provisions in the future, which will be in effect immediately after being posted on this page.

We reserve the right to update or change our Privacy Policy at any time and you should check this Privacy Policy periodically. Your continued use of the Service
after we post any modifications to the Privacy Policy on this page will constitute your acknowledgment of the modifications and your consent to abide by and be bound by the modified Privacy Policy.

If we make any material changes to this Privacy Policy, we will notify you either through the Email address you have provided us, or by placing a prominent notice on our website.

2. What kind of information does this Privacy Policy provide?

This policy, will give you information regarding the Services on:

- How we collect your personal data;
- Why we collect your personal data;
- On what legal basis do we collect your personal data;
- How long do we keep your personal data;
- Your privacy rights;
- What types of personal data we collect.

3. Definitions

"**Duchenne Map**": Duchenne Map is a digital platform that aims to connect the DMD patient community to other stakeholders, offer the opportunity to share advice and knowledge, and to empower patients and carers to take control of their care.

"**Registered User**": Any Patient, Carrier or Caregiver, Patient Organization, Research Organization, Researcher, Care Center, Healthcare Expert, Company who registers in the Duchenne Map and uses the Services.

"**You/Your**": Any user, who visits the DDF Platform and may also refer as Registered User.

"**Services**": All services provided to Registered Users in the context of the Duchenne Map based on the user type.

"**Personal Data**": Anything that identifies a living individual, either on its own or when put together with other information. Examples of personal information are name, address, telephone number, and national insurance number.

"**Sensitive Data**": Sensitive details about an individual, which they would not usually want to be widely known without their consent. Examples of sensitive information are a person's physical or mental health record, genetic or biometric data, racial or ethnic origin, sexuality and political or religious beliefs.

"**Health Data**": Any sensitive data about an individual's past, current and future health status, test, treatments and health care service provision etc., in relation to Duchenne Muscular Dystrophy.

"**Data Processing**": As defined by the General Data Protection Regulation (GDPR) regulation, it covers any operation or set of operations which is performed on personal (health) data or on sets of personal (health) data, whether or not by automated means, such as collection, recording, storage, adaptation or alteration, retrieval, consultation, use, disclosure by

transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction in the context of the Duchenne Map Services.

"**Contact Person**": The physical person that uses the Services on behalf and/or in the name of a Registered User other than an individual.

4. Where do we get your information from?

4.1 Directly from **You upon registration/validation** or while **using** the Duchenne Map.

4.2 The Organization that you are affiliated with: **Patient Organization, Research Organization, Care Center, Company**.

5. Why do we collect Your Personal Data?

5.1 Upon Registration

5.1.1 **Full name, and contact info**: To know who You are and connect you with other Patients, Patient Organizations, Researchers and Healthcare Expert. **You may opt out at all times**.

5.1.2 **Email address**: To verify your account, to send you important Email about relative thematics, and related newsletter subscription. **You may always opt out**.

5.1.3 **Date of birth (if applicable)**:
- To identify the age/clinical status ratio;
- To provide access to the Duchenne Map;
- To generate user classifications of common standards.

5.1.4 **Address:** To identify Registered Users on the map.

5.1.5 **Health Data, and related Sensitive Information:** To deliver the Services and especially to make the best matches and communication channels among **Patients, Patient Organizations, Researchers, and Healthcare Experts**.

5.2 While you use our services:

5.2.1 **Login history and usage data**. For security and performance optimization.

5.2.2 **Communication history**: For security, performance optimization, archiving and statistical purposes.

5.2.3 **Your messages in our contact center**. To keep track of potential issues of the Services,

to provide assistance if you have a problem, to respond to your message, to keep a log of our communication for security reasons.

6. Why we collect your data (basic grounds of processing)

6.1 To know you better and provide **optimized** and **customized services** for maximum **convenience** and **security**.

6.2 **Archiving purposes** that may facilitate you in future **queries**.

6.3 For **communication purposes** as allowed by law and your expressed preferences. **You may always opt out**.

6.4 To **verify** and **validate** your information and all information in the Duchenne Map for maximum **data accuracy** and **safety**.

7. Why are we allowed to process your personal data (Legal Bases)?

Under the GDPR most of the Data Processing is carried out under the lawful basis of 'Public Task' because the processing is necessary for the performance of a task carried out in the Public Interest [GDPR Art.6.(1)(e)]. This allows us to process your Personal Information because it is necessary for public health purposes, and for the purposes of preventive medicine.

We may also process Sensitive Data such as your Health Data because it is necessary for the purposes of preventive medicine, medical diagnosis [GDPR Art.9(2)(h)] and/or for scientific research and statistical purposes [GDPR Art.9(2)(j)].

8. Our rules for collecting your data

- We only use the data to provide the Services with respect to your personal data and the applicable regulation;

- The legal base of the Personal Data collected is based either (a) on Consent (linked with the relevant checkboxes in data collection) or (b) on Contract (linked with the use of the site, data entry, and the terms of use)

- We meet the GDPR requirements and in the country where we provide you with a service via our website or our applications;
- We fully explain why we need the data and how we'll use it (unless we have legitimate reason not to);
- We check and update privacy information on a regular basis (we might also cross-check the data against other database to make sure it's correct);

- We do not share data with anyone unless we have a legal or legitimate reason, or we have permission from you or if you are a child under 16 from your parents;
- We will never sell your data.

9. We may share your data with

- Google analytics;
- Third Parties: In the event we are required to do so we will ensure that we will seek your consent before sharing your personal information with others. If you are unable to consent for any reason we will only share personal information where it is clearly in your best interest to do so.

Legal Authorities: In the event we are forced by law or regulations to do so.

10. How long do we keep your data?

10.1 **Registration data**: ONLY During the period of your registration.

10.2 **Usage data**: ONLY During the period of your registration.

10.3 The criteria used to determine our retention periods include:

10.3.1 As long as the Duchenne Map is **operational** and as long as **you use** our Services and **hold an account** on the Duchenne Map.

10.3.2 Whether there is **a legal obligation** to which we are subject (for example, certain laws require us to keep records of your transactions for a certain period of time before we can delete them).

10.3.3 Whether **retention is advisable** considering our **legal position** (such as, for statutes of limitations, litigation, or regulatory investigations).

10.3.4 In the event you request to **delete your data and any information concerning you** before the set retention periods (when applicable), we may not be able to do so for technical, legal, regulatory, or contractual constraints. Your information **will be retained** to comply with legal and regulatory obligations, as well as for analysis.

10.3.5 We will **destroy** your **personal information** as soon as possible and in a non-restorable, non-re-identifiable manner.

11. Exercise rights

11.1 Your rights:

- Access all personal (health) data you provide to us, in printed or in electronic form free of charge; All your personal (health) data is accessible in your profile. Still if you want us to send you a copy in an electronic form, please send your request on this Email address privacy@duchennemap.org. We will send you a confirmation within 5 days and we will deliver you a copy of your data in an electronic form within 30 days;
- Obtain rectification of any inaccurate or outdated data, or to complete any incomplete data;
- Receive or ask us to provide you or transmit your data in common format;
- Delete your personal (health) data, provided we have no legal obligation to do otherwise;
- Ask for the restriction of any data processing activities;
- Object to certain types of processing including direct marketing, customer profiling, if applicable;
- Submit a complaint to your local Data Protection Authority.

11.2 How to exercise your rights:

- All rights can be exercised by submitting a written request via Email free of charge privacy@duchennemap.org;
- Our designated DPO will respond to your request within thirty (30) calendar days;
- We can only identify you via your Email address and we can only adhere to your request and provide information if we have Personal (Health) Data about you through you having made contact with us directly and/or you using our site and/or services. We cannot provide, rectify or delete any data that we store on behalf of our users or customers.

12. Complaints about our behavior

12.1 You have the **right to complain** if you don't feel we are living up to our responsibilities when it comes to your data.

12.2 We have an appointed **Data Protection Officer (DPO)**, who takes your complaint very seriously. You can contact our appointed DPO on this Email address privacy@duchennemap.org We will send you a confirmation within 5 days and do our very best to deal with the issue within 30 days. If the issue is difficult or requires a lot of work it may take longer, but we will keep you updated.

12.3 You always have the **right to complain** to the authorities as well, but because we take privacy matters very seriously, we would really appreciate it, if you would talk to us.

12.4 You can complain about:

- How your personal data has been processed;
- How your request for access to data has been handled;
- How your complaint has been handled;
- Appeal against any decision made following a complaint.

13. Overseas Transfers of Your Personal Data

Your personal data will be stored on a Cloud Center. Your personal data will not be transferred to countries outside the EU.

References

Article 4(2) and (6) of the GDPR

Appendices

Appendix 1

What types of Personal Data we collect
The data we collect depends on the types of Registered Users.

4.1 Patient, Carrier or Caregiver Data Fields:

4.1.1 Patient, Carrier or Caregiver – Registration: Email address, Address.
- Permission to be contacted by other patients
  (checkbox)
- Permission to be contacted by Patient Organizations (checkbox)

4.1.2 Patient – Data: I am an adult patient, carrier or a caregiver (checkbox), Phone, Birthday, Gender, Address

4.1.3 Patient – Medical Details: Patient First Name, Patient Last Name, Gender, Birthday

4.1.3.1 Disease type (checkbox)

- Duchenne Patient
- Becker Patient
- Duchenne Carrier
- Becker Carrier

4.1.3.2 Ambulation status (checkbox)

- Ambulatory
- Non-ambulatory

4.1.3.3 Use of ventilation (checkbox)

4.1.3.4 Mutation type/exon (checkbox/enter a value between 1 and 79)

- small deletion (S)

- small insertion (S)
- point mutation (S)
- large deletion (L)
- large duplication (L)

4.1.3.5 Corticosteroids (checkbox)
- Daily
- Every other day
- Weekend
- Rarely
- Used in the past
- Never used

4.2 Patient Organization Data Fields:

4.2.1 Patient Organization – Registration: Patient Organization Name, Email address, Address.

4.2.2 Patient Organization – Account details: Patient Organization Name, Website, Social media profiles, Address, Phone.

4.2.2.1 Contact Person

- First name
- Last name
- Email address
- Title
- Phone

4.2.2.2 Add a Team Member

- First name
- Last name
- Patient Organization Role (Choose from a drop-down menu e.g. chair, board member, etc)
- Email address
- Phone

4.2.2.3 Number of patients (Duchenne or Becker).

4.2.2.4 Services provided by the Patient Organization (Choose from a drop-down menu e.g., social work, Psychology, etc.).

4.2.2.5 My Projects.

- Title
- Acronym
- Type (Choose from a drop-down menu e.g., Advocacy/Awareness, Research, Policy etc.).
- Start Date
- End Date
- Status (Choose from a drop-down menu e.g., Active, Completed, Aborted).
- Website URL
- Project Manager Contact Details
- First Name
- Last Name
- Email
- Phone
- Objectives
- Partners
- Check box /Select from a list of validated researchers and healthcare experts in the platform
- Name
- URL
- Results
- Check box /Select from a list of added research publications in the platform
- Research Publications (Choose from a drop-down menu)

4.2.2.6 My Publications.

- Title
- Category (Choose from a drop-down menu, Advocacy/Awareness Basic, Research Preclinical, Policy Clinical)
- Authors
    - Author Type (Choose from a drop-down menu, Researcher, Healthcare expert, Other)
    - Researcher (select from list of validated researchers in the platform - Choose from a drop-down menu)
- Short Summary
- Link to Publication
- Journal

- Publication Date
- Tags

4.2.2.7 My Clinical Trials

Clinical Trial ID

4.2.2.8 Investigational Medicinal Product (IMP)

4.3 Research Organization Data Fields:

4.3.1 Research Organization – Registration: Research Organization Name, Email address, Address.

4.3.2 Research Organization – Account details: Research Organization Name, Address, Phone, Website.

4.3.2.1 Contact Person

- First name
- Last name
- Email address
- Title
- Phone

4.3.2.2 Affiliated Researcher

- (Choose from a list of validated Researchers that are connected to your Research Organization or type in the open field).

4.3.2.3 Affiliated Healthcare Expert

- (Choose from a list of validated Healthcare Experts that are connected to your Care Center or type in the open field).

4.3.2.4 Add a new Researcher – Account details

- First name

- Last name
- Address
- Phone
- Title
- Website
- Research type (checkbox)

     o Basic
     o Preclinical
     o Clinical
     o Therapy
     o Device
     o Care
     o Health Economics
     o Other (open text)

- Interests (Choose from a drop-down menu e.g., gene replacement, exon skipping, etch).

- Specialization (Choose from a drop-down menu e.g., Biologist, Medical, etc.).

4.3.2.5 My Clinical Trials.

Clinical Trial ID

4.3.2.6 My Projects.

- Title
- Acronym
- Type (Choose from a drop-down menu e.g., Advocacy/Awareness, Research, Policy etc.).
- Start Date
- End Date
- Status (Choose from a drop-down menu e.g., Active, Completed, Aborted).
- Website URL
- Project Manager Contact Details
- o First Name
- o Last Name
- o Email
- o Phone
- Objectives
- Partners
- o Check box /Select from a list of validated researchers and healthcare experts in the platform

- o Name
- o URL
- ● Results
- o Check box /Select from a list of added research publications in the platform
- o Research Publications (Choose from a drop-down menu)

4.3.2.7 My Publications.
- Title
- Category (Choose from a drop-down menu, Advocacy/Awareness Basic, Research Preclinical, Policy Clinical)
- Authors
  - o Author Type (Choose from a drop-down menu, Researcher, Healthcare expert, Other)
  - o Researcher (select from list of validated researchers in the platform - Choose from a drop-down menu)
- Short Summary
- Link to Publication
- Journal
- Publication Date
- Tags

4.3.2.8 Investigational Medicinal Product (IMP).

4.4 Researcher Data Fields:

4.4.1 Researcher – Registration: Email address, Address.

4.4.2 Researcher – Account details:

- First name
- Last name
- Address
- Phone
- Title
- Website
- Research type (checkbox)

      o Basic

      o Preclinical

      o Clinical

      o Therapy

      o Device

      o Care

      o Health Economics

      o Other (open text)

• Interests (Choose from a drop-down menu e.g. gene replacement, exon skipping, etc.).

• Specialization (Choose from a drop-down menu e.g., Biologist, Medical, etc.).

4.4.2.1 Affiliated Research Organization

• (Choose from a list of validated Research Organizations or type in the open field).

4.4.2.2 Affiliated Care Center

• (Choose from a list of validated Care Centers or type in the open field). **4.4.2.3**

Affiliated Patient Organization

• (Choose from a list of validated Patient Organizations or type in the open field).

4.4.2.4 My Clinical Trials.

Clinical Trial ID

4.4.2.5 My Projects.

- Title
- Acronym
- Type (Choose from a drop-down menu e.g., Advocacy/Awareness, Research, Policy etc.).
- Start Date
- End Date
- Status (Choose from a drop-down menu e.g., Active, Completed, Aborted).
- Website URL
- Project Manager Contact Details

- o First Name
- o Last Name
- o Email
- o Phone
- ● Objectives
- ● Partners
- o Check box /Select from a list of validated researchers and healthcare experts in the platform
- o Name
- o URL
- ● Results
- o Check box /Select from a list of added research publications in the platform
- o Research Publications (Choose from a drop-down menu)

4.4.2.6 My Publications.
- • Title
- • Category (Choose from a drop-down menu, Advocacy/Awareness Basic, Research Preclinical, Policy Clinical)
- • Authors
    - o Author Type (Choose from a drop-down menu, Researcher, Healthcare expert, Other)
    - o Researcher (select from list of validated researchers in the platform - Choose from a drop-down menu)
- • Short Summary
- • Link to Publication
- • Journal
- • Publication Date
- • Tags

4.4.2.7 Investigational Medicinal Product (IMP).

4.5 Care Center Data Fields:

4.5.1 Care Center – Registration: Care Center Name, Email address, Address.

4.5.2 Care Center – Account Details: Care Center Name, Address, Phone, Website.

4.5.2.1 Contact Person

- First name
- Last name
- Email address
- Title
- Phone

4.5.2.2 Duchenne Care Center Certification

- (CCDC Certification) (checkbox)

4.5.2.3 Member of EURO-NMD ERN (checkbox)

4.5.2.4 Services provided by the Care Center (Choose from a drop-down menu e.g., Audiology, Cardiology, etc.).

4.5.2.5 Affiliated Healthcare Expert

- (Choose from a list of validated Healthcare Experts that are connected to your Care Center Organization or type in the open field).

4.5.2.6 Affiliated Researcher

- (Choose from a list of validated Researchers that are connected to your Research Organization or type in the open field).

4.5.2.7 Add a new Healthcare Expert

- First name
- Last name
- Email address
- Title
- Address
- Specialties (Choose from a drop-down menu e.g. Audiology, Cardiology, etc.).

4.5.2.8 Number of patients (Duchenne or Becker).

4.5.2.9 Affiliated Patient Organization

• (Choose from a list of validated Patient Organizations or type in the open field).

4.5.2.10 Affiliated Research Organization

• (Choose from a list of validated Research Organizations or type in the open field).

4.5.2.11 Affiliated Care Center

• (Choose from a list of validated Care Centers or type in the open field). **4.6**

Healthcare Expert Data Fields:

4.6.1 Healthcare Expert – Registration: Email address, Address.
4.6.2 Healthcare Expert – Account Details: Title, Address,
Phone, Website.

4.6.2.1 Healthcare Experts Specialties (Choose from a drop-down menu e.g. Cardiologist, Developmental pediatrics, etc.)

4.6.2.2 Affiliated Care Center

• (Choose from a list of validated Care Centers or type in the open field). **4.6.2.3**

Affiliated Research Organization

• (Choose from a list of validated Research Organizations or type in the open field).

4.6.2.4 Affiliated Patient Organization

• (Choose from a list of validated Patient Organizations or type in the open field).

4.6.2.5 My Clinical Trials.

Clinical Trial ID

4.6.2.6 My Projects.

- Title
- Acronym
- Type (Choose from a drop-down menu e.g., Advocacy/Awareness, Research, Policy etc.).
- Start Date
- End Date
- Status (Choose from a drop-down menu e.g., Active, Completed, Aborted).
- Website URL
- Project Manager Contact Details
  o First Name
  o Last Name
  o Email
  o Phone
- Objectives
- Partners
  o Check box /Select from a list of validated researchers and healthcare experts in the platform
  o Name
  o URL
- Results
  o Check box /Select from a list of added research publications in the platform
  o Research Publications (Choose from a drop-down menu)

4.6.2.7 My Publications.
- Title
- Category (Choose from a drop-down menu, Advocacy/Awareness Basic, Research Preclinical, Policy Clinical)
- Authors
  o Author Type (Choose from a drop-down menu, Researcher, Healthcare expert, Other)
  o Researcher (select from list of validated researchers in the platform - Choose from a drop-down menu)
- Short Summary
- Link to Publication
- Journal
- Publication Date
- Tags

4.6.2.8 Investigational Medicinal Product (IMP).

4.7 Company Data Fields:

4.7.1 Company – Registration: Company name, Email address, Address.
4.7.2 Company – Account details: Company name,
Address, Phone, Website, social media.

4.7.2.1 Contact Person

- First name
- Last name
- Email address
- Title
- Phone
- Department ((Choose from a drop-down menu e.g., Access, Advocacy, etc.)

 4.7.2.2 Add a new Staff Member

- First name
- Last name
- Email address
- Title
- Address
- Department ((Choose from a drop-down menu e.g., Access, Advocacy, etc.)

4.7.2.3 Add a new affiliated Entity

- Type - National, Regional, Headquarters (Choose from a drop-down menu)

- Name
- Address
- Phone
Email
- Website
Contact person
First Name
Last Name
Email
Phone
Title

4.7.2.4 Add a new Staff Member from the Affiliated Entity

• First name
• Last name
• Email address
• Title
• Address
• Department ((Choose from a drop-down menu e.g., Access, Advocacy, etc.)

4.7.3 My Clinical Trials.

Clinical Trial ID

4.7.4 My Projects.

● Title
● Acronym
● Type (Choose from a drop-down menu e.g., Advocacy/Awareness, Research, Policy etc.).
● Start Date
● End Date
● Status (Choose from a drop-down menu e.g., Active, Completed, Aborted).
● Website URL
● Project Manager Contact Details
o First Name
o Last Name
o Email
o Phone
● Objectives
● Partners
o Check box /Select from a list of validated researchers and healthcare experts in the platform
o Name
o URL
● Results
o Check box /Select from a list of added research publications in the platform
o Research Publications (Choose from a drop-down menu)

4.7.5 My Publications.
• Title
• Category (Choose from a drop-down menu, Advocacy/Awareness Basic, Research Preclinical, Policy Clinical)
• Authors

- o Author Type (Choose from a drop-down menu, Researcher, Healthcare expert, Other)
- o Researcher (select from list of validated researchers in the platform - Choose from a drop-down menu)
- Short Summary
- Link to Publication
- Journal
- Publication Date
- Tags

4.7.6 My Investigational Medicinal Products (IMP).