



Duchenne **UK**
Connect

A health platform and app to empower people with Duchenne muscular dystrophy and accelerate research and future treatments.



In collaboration with



Duchenne
UK



duchenneukconnect.org

Contents

1. What is Duchenne UK Connect?
2. Why is Duchenne UK Connect important?
3. Who can join and do I have to take part?
4. What joining involves
5. Research and use of your information
6. Benefits, burdens and possible risks
7. How we protect your information
8. Who may have access to information?
9. Your choices and withdrawing
10. How Duchenne UK Connect is run
11. Questions, concerns and complaints
12. Help, support and contact details

**Joining Duchenne UK Connect is simple.
Watch our video to learn more.**



1. What is Duchenne UK Connect?

Duchenne UK Connect is a first-of-its-kind App that has been developed specifically for the Duchenne community in the UK.

The App brings together everything patients need, in one easy to use platform. This includes the best guidance on care; what to do in an emergency; how to find out about research and clinical trial opportunities and the ability to register to take part in clinical trials.

Duchenne UK Connect can be accessed on a phone, tablet or computer. It is designed to help people with Duchenne and their families keep important information in one place, stay organised, prepare for emergencies, find reliable care information and learn about and participate in research.

The platform has different modules. You can choose which parts you want to use and will be asked for consent where this is required.

The main parts of the platform

Module	What it can help you do	
Registry	Share information about health, care and everyday life. This can help build a clearer picture of Duchenne and how people's needs change over time.	 Duchenne UK Connect
Research	Find Duchenne Hub UK research studies and clinical trials and, if you wish, register your interest in being contacted about possible opportunities.	Duchenne Hub UK FOR CLINICAL RESEARCH  
Care	Access trusted care recommendations and practical patient and family guides based on the work of Duchenne Care UK.	Duchenne Care UK BEST CARE FOR ALL  
In Case of Emergency (ICE)	Create a personalised in case of emergency profile containing essential medical information, which you can quickly access and show to healthcare professionals in an emergency situation.	

BUILT WITH THE COMMUNITY People with Duchenne, parents, caregivers and clinicians have helped shape the design of Duchenne UK Connect.

OUR COMMITMENTS TO YOU



- We will always put the interests of people with Duchenne and their families first.



- People with lived experience of Duchenne will be involved in how Duchenne UK Connect is governed and how important decisions are made.



- We will only support research that aims to benefit people with Duchenne.



- We will never share your data with any unauthorised third parties.



- We will be open about how Duchenne UK Connect works and will tell you about any important changes.



- We will protect your privacy and keep your information safe.



2. Why is joining Duchenne UK Connect important?

Designed with families, for families

Whether you're living with Duchenne or caring for someone who is, Duchenne UK Connect gives you the knowledge, tools and confidence to take an active role in your healthcare journey.

Help shape the future of care and treatment for Duchenne

By choosing to share information through the Duchenne UK Connect platform, you can help researchers better understand Duchenne, improve access to clinical trials and accelerate the development of future treatments. Every family's contribution makes a difference.

With your permission, the information collected through Duchenne UK Connect may be used to:

- better understand Duchenne and how it affects different people;
- learn how Duchenne changes over time;
- understand its impact on health, wellbeing and quality of life;
- support research into new and better treatments;
- improve the planning and delivery of health and care services; and identify where care and support could be improved.

This may not benefit you personally, but it could help improve research, care and support for people living with Duchenne now and in the future.

Secure. Trusted. In your control.

Your information is protected with secure registration, two-step authentication and user-controlled consent, giving you confidence that your data remains safe.

The benefits of sharing information



3. Who can join and do I have to take part?

Why am I being invited?

You are being invited to join Duchenne UK Connect because you live in the UK and either:

- you have been diagnosed with Duchenne muscular dystrophy; or
- you are the parent or legal guardian of a child with Duchenne.
- you are a caregiver or authorised person supporting someone with Duchenne, where appropriate.

Do I have to join?

No. Joining Duchenne UK Connect is entirely your choice. You may wish to discuss your decision with your family, friends or healthcare team. If you join and later change your mind, you can stop using some parts of the platform or withdraw completely. Please see section, 'Your choices and withdrawing'.

What if I am a parent or legal guardian?

A parent or legal guardian may create and manage an account for a child with Duchenne. You should involve the child in decisions in a way that is appropriate for their age and understanding. As the child gets older, the way the account and consent are managed may need to change.

When a participant turns 16, they will be asked to provide their own consent to continue where they are able to do so. They may manage the account themselves or authorise a parent, caregiver or trusted person to continue helping them. A separate process will apply if the participant cannot provide informed consent.

What if I need help deciding?

You can ask questions before deciding. Contact the Duchenne UK Connect team using the details at the end of this leaflet. The team can explain the platform but cannot give personal medical advice.



4. What joining involves

What will I be asked to do?

1. Create a secure account and provide basic details about yourself or the person with Duchenne.
2. Read the participant information sheet(s) and complete the consent form(s) for the parts of Duchenne UK Connect you want to use.
3. Choose which parts you want to join. You do not have to agree to every part.
4. If you join the Registry, answer questions about diagnosis, genetics, health, treatments, mobility, daily activities, care, wellbeing and quality of life.
5. If you wish, provide information about your diagnosis, by uploading documents such as genetic reports, clinic letters or medication information.
6. Join the Care module to create an emergency profile and download or share it with people involved in your care.
7. Join the Research module to learn more about research studies in DMD taking place in the UK and to register your interest in taking part in clinical trials.
8. Update information from time to time, usually every six months or when you are invited to complete a follow-up questionnaire.

Do I have to answer every question?

Some questions need to be answered to make a particular part of the platform work. These will be clearly marked with a red asterisk. Other questions may be optional. You can stop and return later. If a question is optional, you do not have to answer it if you feel uncomfortable or do not want to.

Some questions are needed to make a particular part of the platform work. These will be clearly marked. Other questions may be optional. If a question is optional, you do not have to answer it if you feel uncomfortable or do not want to. You can leave at any time, save your progress and return later to complete any remaining questions.

How often will you contact me?

We may contact you from time to time to check that you are still using your account, send you important messages about your account, or remind you to update your information.

We may also contact you about changes to Duchenne UK Connect. If you have chosen to receive them, we may send you information about research opportunities and other updates.

You can change your communication preferences in your account at any time. However, some important messages about your account, consent, privacy or security are necessary and cannot be turned off while you continue to use Duchenne UK Connect.

ENTER INFORMATION ONCE Where possible, information entered in one part of Duchenne UK Connect will automatically be entered in relevant fields in other parts. This is intended to save time and avoid asking you for the same information again.

5. Research and use of your information

How may my information be used for research?

If you consent to participate in the registry and/or research module, information you provide may be used to support researchers answer questions about Duchenne. This may include understanding symptoms and progression, care and service use, treatments, wellbeing, quality of life and the experiences of people with Duchenne and their families.

Research may be carried out by approved researchers from universities, the NHS, charities, public bodies or commercial organisations such as pharmaceutical and technology companies.

How is research approved?

Requests to use information will be reviewed through Duchenne UK Connect's governance process. The Data Access Committee includes people with lived experience of Duchenne and relevant professional or research expertise. It will consider whether the proposed work is scientifically and ethically appropriate, has a clear purpose and has suitable safeguards.

Researchers will receive only the information needed for the approved work. Identifying details, such as your name and contact details, will only be provided where absolutely necessary for the approved research and subject to appropriate review and safeguards. None of this will be given without your consent.

Where you have provided specific consent, information may also be linked to trusted national datasets, such as NHS datasets, or international registry networks such as TREAT-NMD. Privacy-preserving processes and appropriate approvals will be used.

Clinical trials and other studies

If you join the research module, you can use the Clinical Trial Finder to see current and upcoming Duchenne muscular dystrophy (DMD) clinical trials in the UK. The Clinical Trial Finder is for information only. Seeing a study listed does not mean that you or your child will be eligible or that the study will be suitable for you.

You may also choose to complete the clinical trials expression of interest form (also known as CRD) questionnaire. The information you provide can be used to help identify studies that you or your child may be suitable for and to help clinical sites and researchers find potential participants.

This is the service previously provided through the Central Recruitment Database (CRD), which is now part of Duchenne UK Connect.

If you or your child appear to meet the initial requirements for a study, and there is space available at a participating site, you may be contacted

about the study. Being contacted does not mean that you or your child will definitely be able to take part. The research team running the study will explain the study to you, check whether you or your child meet the full eligibility criteria, and ask for separate consent before you take part.

YOUR CHOICE If you are contacted about a research study, you do not have to take part. Saying no will not affect your or your child's care, or your ability to take part in future research.

Will research findings identify me?

Research findings may be published in reports, presentations, academic journals or other public materials. These will be prepared so that people will not be able to identify you. Direct quotations will only be used in line with the consent you have given and will normally be anonymised.

6. Benefits, burdens and possible risks

Possible benefits

- Accessing trusted care information and patient and family guides.
- Finding UK clinical trials and other research opportunities more easily.
- Helping build knowledge and understanding of DMD that may improve future research, care and services.
- Keeping important health and care information organised in one place.
- Creating an emergency profile that can be quickly viewed or shared with medical teams and others when needed.
- Helping the Duchenne community be better represented in research.

These benefits are not guaranteed. Duchenne UK Connect does not replace your medical record, healthcare team or emergency services.

Possible burdens and risks

- **Time and effort:** Creating an account, completing questionnaires and keeping information up to date takes time.
- **Sensitive or upsetting questions:** Some questions may make you feel uncomfortable, worried or upset.
- **Privacy and security:** Strong safeguards will be used, but no digital system can remove the risk of unauthorised access completely.
- **Research contact:** You may receive information about a study that is not suitable for you or that you later decide not to join.
- **No personal medical advice:** Information shown on the platform is general. It should not be used instead of advice from your healthcare team.
- **Future risks:** New uses of technology or new types of research may create risks that are not yet known. Important changes will be communicated and additional consent will be sought where required.

IF YOU FEEL DISTRESSED Stop the questionnaire or activity and speak to someone you trust. For medical or emotional support, contact your healthcare team or an appropriate support service.

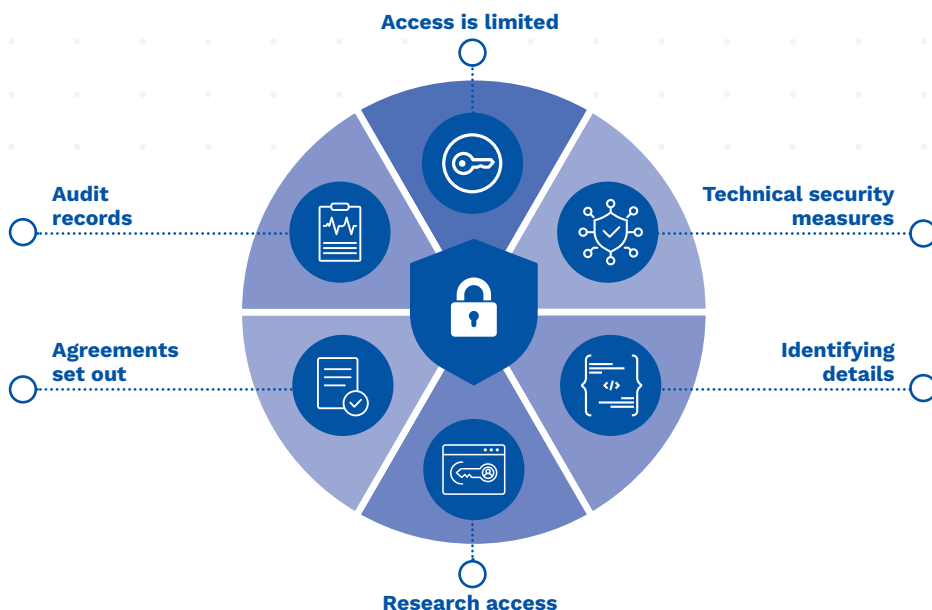
7. How we protect your information

What information may be collected?

Depending on the modules you participate in, Duchenne UK Connect may collect:

- account and contact details;
- details about your/your child's condition and medical history; information about medicines, treatments, equipment and care;
- information about mobility, daily activities, wellbeing and quality of life;
- documents or emergency information you choose to add;
- technical and security information needed to protect your data.

How is your information kept safe?



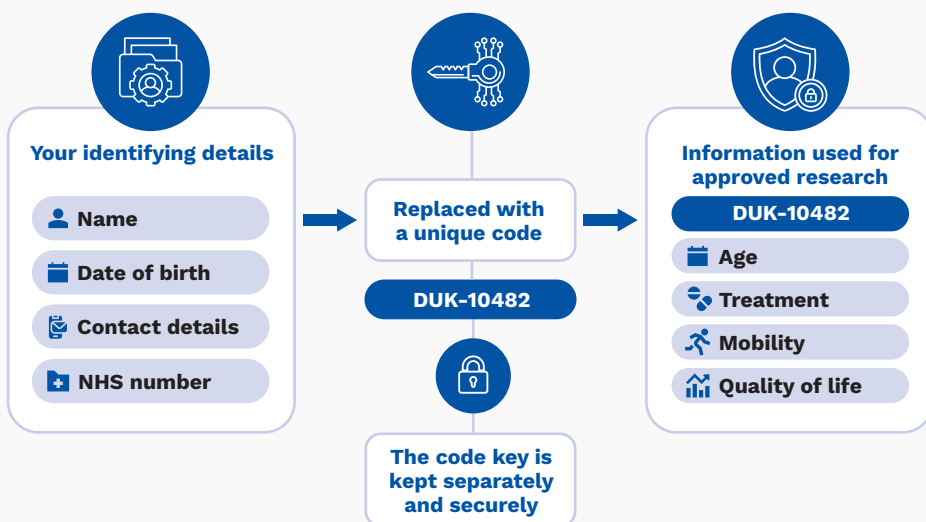
- Access is limited to authorised people who need it for their role.
- Technical security measures are used to protect information when it is stored and transferred.
- Identifying details are separated or replaced with a code where appropriate.
- Research access is reviewed and controlled.
- Agreements set out how approved organisations must protect and use information.
- Audit records help monitor access and changes.

Platform information is stored on UK-hosted servers. Access is password-protected and restricted according to each person's authorised role.

What does pseudonymised mean?

Pseudonymised information has identifying details, such as your name and contact details, removed and replaced with a code. The code can be linked back to you only by authorised people using information kept separately and securely. Pseudonymised information is still personal data and remains protected by data protection law.

How pseudonymisation helps protect your information



Researchers usually see coded information, not your name or contact details



Important: Pseudonymised information can still be linked back to you by authorised staff. It is not anonymous and remains protected as personal data.

How long will my information be kept?

Information about you will be kept only for as long as needed for the purpose explained to you, to meet research and legal requirements, and in line with Duchenne UK's retention arrangements. The relevant privacy notice gives more detail. Some research records may need to be kept after you withdraw so that completed research remains reliable and can be audited.

8. Who may have access to information?



Duchenne UK

A limited number of authorised Duchenne UK staff may access identifiable information where needed to operate the platform, support you, manage consent, protect security or oversee approved research.

Newcastle University and Duchenne Hub UK

The research module includes services developed with the John Walton Muscular Dystrophy Research Centre at Newcastle University, including the clinical trials expression form, also known as the Central Recruitment Database (CRD) and the Clinical Trial Finder.

Duchenne UK and Newcastle University look after the CRD together and jointly decide how the information in it is used. This means that, for the CRD, both organisations are responsible for protecting your information and for making sure it is used properly. In data protection law, they are called “joint controllers”.

Service providers

Specialist organisations may process information on behalf of Duchenne UK or Newcastle University to host, maintain, secure or support the platform. They must follow written instructions, protect the information and use it only for the agreed service.

Approved researchers

Approved researchers may access only the information needed for their approved study, usually without identifying details. Access may be provided under a data sharing or access agreement and may take place in a controlled environment.

Sharing information with healthcare professionals, schools, family members and emergency services

Your information will not be made available to employers, insurers, educational institutions, family members or other organisations unless you choose to share it, consent to a specific disclosure, or disclosure is required by law. You may choose to share selected information or documents with people involved in your care or support.

Will information be sent outside the UK?

The live platform is hosted in the UK. If an approved activity requires personal information to be accessed or transferred outside the UK, this will only happen where permitted by data protection law, with appropriate safeguards and in line with the consent and privacy information provided to you.

Your participation on the platform & how you can withdraw

What can I participate in?

Duchenne UK Connect is made up of different modules. Where possible, you can choose which modules to take part in and what information you provide.



You can also let us know how you want to be communicated with.

Can I withdraw?

Yes. You can withdraw from Duchenne UK Connect or from a particular part at any time without giving a reason. Withdrawing will not affect your healthcare or support.

When you ask to withdraw, we will explain what can be stopped or deleted and what may need to be kept. This depends on which part you joined and whether information has already been used in research.

What happens to information already used?

We may not be able to remove information that has already been included in completed analyses, research results or data already provided for an approved study. Removing it could make the research unreliable. We will not use identifiable information for new purposes after withdrawal unless there is another lawful reason and you have been informed.

Can I delete my account but keep an emergency profile or other information?

Your options may differ between parts of the platform. Contact the Duchenne UK Connect team before deleting your account if you want to understand what will happen to information, uploaded documents, research preferences or an emergency profile.

Your data protection rights

Depending on the circumstances, you may have rights to ask for access to your personal information, correction, deletion, restriction, portability or to object to certain uses. Some rights may be limited where information is needed for research and appropriate safeguards are in place. The privacy notice explains these rights and how to use them.

HOW TO WITHDRAW Use the withdrawal or account options provided in the Duchenne UK Connect platform, or contact Duchenne UK using the details at the end of this leaflet. We will ask you to confirm your identity before making changes.

10. How Duchenne UK Connect is run and funded

Who is responsible?

Duchenne UK is responsible for the overall Duchenne UK Connect platform and for deciding how personal information is used for the parts it controls.

Newcastle University has responsibilities for the central recruitment database within the Research module, as explained in the relevant privacy notice.

Governance

Duchenne UK Connect is overseen through governance arrangements that include people with lived experience of Duchenne and relevant clinical, research, data and charity expertise. These arrangements include:

- a Steering Committee that reviews the direction and operation of the programme
- a Data Access Committee that reviews requests to use information
- a Central Recruitment database (CRD) Steering Committee

Patient involvement

Members of the public with lived experience of the disease have been and will continue to be involved in the development of Duchenne UK Connect. This includes focus groups, interviews, a patient panel, in our governance and on our Data Access Committee and CRD Steering Committee.

Funding and charges

Duchenne UK Connect is funded and operated by Duchenne UK, with additional support through the PaLaDIn project. PaLaDIn is supported by the Innovative Health Initiative Joint Undertaking under grant agreement No. 101132943, with support from the European Union's Horizon Europe programme



and participating partners. It also receives UK support through the government's Horizon Europe funding guarantee.

Additional academic, charitable, public or appropriate industry funding may support the platform in future. Funding will be managed through Duchenne UK's governance processes and will not give a funder automatic access to personal information. Any funder wishing to access data must follow the same application, review and approval procedures as any other organisation. Funding will not influence access decisions.

An organisation may be asked to contribute to the reasonable costs of preparing or providing access to information for approved research. Payment does not guarantee approval and does not allow an organisation to identify or contact you.

What will happen to research findings?

Research may lead to intellectual property, products or services from which an organisation could benefit financially. You will not normally receive payment or a share of any profit arising from research that uses information you contributed.



11. Questions, concerns and complaints

What if I have a question or problem?

Please contact Duchenne UK first. The team will try to answer your question or resolve the problem as soon as reasonably possible. Contact details are in section 12.

What if I want to complain about the research?

You can contact Duchenne UK and ask for your concern to be reviewed under its complaints process. If your concern relates to a particular research study, you may also contact the study team using the details provided for that study.

What if I have a concern about my personal information?

You can contact Duchenne UK's data protection contact using the details in the privacy notice or by writing to Duchenne UK at the address below. You also have the right to complain to the Information Commissioner's Office, the UK regulator for data protection.

- Website: ico.org.uk/make-a-complaint
- Telephone: 0303 123 1113

You do not have to contact Duchenne UK before contacting the Information Commissioner's Office, although giving Duchenne UK an opportunity to address the issue may resolve it more quickly.

Has the project been independently reviewed?

Duchenne UK Connect has been reviewed through the appropriate UK research ethics and governance processes. Any separate clinical trial or research study offered through the platform will have its own approvals and participant information.

12. Help, support and contact details



Your most important resources are your GP and hospital team. They know your medical history and are best placed to advise you.

Medical help

Duchenne UK Connect does not provide emergency medical advice or replace advice from your healthcare team.

- For urgent medical care, contact NHS 111 or your usual clinical team.
- In an emergency, call 999.
- For questions about your treatment or care, contact your neuromuscular team, GP or other healthcare professional.

Duchenne UK Connect and general enquiries

Study email: duchenneukconnect@duchenneuk.org, 07467 856878

Research module and Central Recruitment Database: dmdhub@ncl.ac.uk, 0191 241 8621

Website: www.duchenneuk.org

Post:

Duchenne UK, Unit G24 Shepherd's Building,
Charecroft Way,
Hammersmith, London W14 0EE

Data protection contacts

Duchenne UK Data Protection Officer: dataprotection@duchenneuk.org
Newcastle University Data Protection Officer for the Research module:
nrecman@ncl.ac.uk

Principal Investigator

Professor Michela Guglieri, John Walton Muscular Dystrophy Research Centre, Translational and Clinical Research Institute, Newcastle University, International Centre for Life, Central Parkway, Newcastle upon Tyne NE1 3BZ

About Duchenne UK

Duchenne UK is a charity working to create a future without Duchenne muscular dystrophy while supporting people affected by Duchenne today. It funds and accelerates research, helps expand access to clinical trials, supports improvements in care and works with the Duchenne community, clinicians, researchers and partners.

Registered charity in England and Wales: 1147094

Company limited by guarantee, registered in England: 8030768
Before you decide, take as much time as you need to read this leaflet and the consent information for the modules you wish to join.



Notes



Duchenne **UK** Connect



Find out more and download at
duchenneuk.org/duchenne-uk-connect

duchenneukconnect@duchenneuk.org



Duchenne UK Connect is developed and funded by Duchenne UK and run in collaboration with our partners at the John Walton Muscular Dystrophy Research Centre at Newcastle University.



**Duchenne
UK**



Duchenne UK is a registered charity no. 1147094. A non profit company limited by guarantee.
Registered in England no. 8030768.