PaLaDIn
Patient Lifestyle & Disease Data Interactium

Introduction to the Patient and Caregiver User Group

This document provides details about PaLaDIn, and sets out why we are setting up a Patient and Caregiver User Group, how the group will function and who can join the group.

For any enquiries or clarifications please contact helen.wade@treat-nmd.com

This project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No 101132943. The JU receives support from the European Union's Horizon Europe research and innovation programme, COCIR, EFPIA, EuropaBio, MedTech Europe, Vaccines Europe (and the FSHD Society and TREAT-NMD Services Ltd as contributing partners participating in the project). The project will also receive funding from UK Research and Innovation (UKRI) under the UK government's Horizon Europe funding guarantee [grant numbers 10105921, 10103989, and 10083579.

What is PaLaDIn?

PaLaDIn is a scientific project that aims to enhance healthcare outcomes for individuals with neuromuscular diseases through the development of the Interactium®, a global, patient-centric data platform.

By gathering comprehensive patient data on health status and experiences, we will ensure that patients' voices are integral to healthcare decision-making.

Our platform aims to accelerate the development of effective treatments, improve patient-reported outcome measures (PROMs), and inform healthcare decisions. Ultimately, we strive to share our insights and tools to benefit other rare diseases, empowering patients and advancing better healthcare outcomes. For further information on the PaLaDIn Project, please visit the project website.

What is the Interactium?

The Interactium® is an innovative type of data platform.

Patients and caregivers will be able to access the Interactium® via their patient registry to submit data that's important to them about their condition and lived experience. The platform will be secure, user friendly and will have accessible dashboards that will allow patients to clearly view their data.

In rare disease research, most of the data currently collected comes from clinical settings, such as hospitals and medical facilities. This type of data often focuses on the medical aspects of the condition, like diagnostic tests and treatments, but it doesn't always capture the personal experiences of patients.

PaLaDIn will try to change this by linking together clinical data collected in patient registries with data submitted by patients about how their condition affects their daily lives. By doing this, data from the Interactium® that includes data that is important to patients could be used by researchers to develop better treatments and care guidelines. This data could also be used to better inform health care decision making.

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What is the Patient and caregiver user group?

An objective of PaLaDIn is to be a patient-centric project with a commitment to utilise co-creation methodologies with patients to build the Interactium. To deliver effectively on these aims, it is essential to establish a Patient and Caregiver User Group (PCUG) for the project.

We aim to bring together people with different experiences and backgrounds from across the neuromuscular disease space, and we plan to establish a group which includes patients and caregivers from the following NMD disease communities:

- Becker muscular dystrophy (BMD)
- Duchenne muscular dystrophy (DMD)
- Facioscapulohumeral muscular dystrophy (FSHD)
- Limb-girdle muscular dystrophy (LGMD)
- Myotonic dystrophy (DM)
- Spinal muscular atrophy (SMA)

What will the Patient and Caregiver User Group do?

The members of the group will play a critical role in co-creation of the Interactium® and other resources developed within PaLaDIn by providing patient perspective and feedback on the work of the project.

It is expected that the PCUG will meet virtually and in-person if budget and timing allows. You should expect to meet via virtual call once every two months (during working hours) for 60-minute meetings. In addition to this, ad-hoc meetings may be organised in order to get involved in other PaLaDIn engagement activities, up to a maximum of 60 minutes every two weeks.

The topics for engagement may include (but are not limited to):

- Educational resources and toolkits
- Patient reported outcomes and patient reported outcome measures
- Knowledge translation (the process of moving research findings into practical application to improve healthcare delivery and patient outcomes)
- Dataset development
- Attendance and participation in planned workshops
- Interactium data platform design, prototype and build
- Communications and reaching and engaging with patients

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Experience and Skills of User Group Members

We are looking for applications to join the PCUG from people who have the following experience and skills:

- Patients, patient advocates or caregivers with a lived experience of one of the neuromuscular diseases listed above.
- Experience or interest in being involved in an EU project.
- Be willing and confident to participate in discussions which will be held in English, share views and provide feedback during workshops, events and focus groups.
- Interest in the key topics listed above, especially an interest in the development of a data platform that utilises patient data with the goal of accelerating the development of effective treatments and patient care, enhance healthcare decision-making and improving patient outcomes.
- Maintaining confidentiality: PCUG members will be required to sign a Confidential Disclosure Agreement (CDA).
- Members must be confident and clear communicators in written and spoken English.

Members of the PCUG do not need to have previous experience or formal expertise in the key topics or in patient and public involvement and engagement (PPIE). We are looking for wide range of skills and experience to ensure a broad range of perspectives are represented.

Will I be paid for taking part in the Patient and Caregiver User Group?

To recognise the support that you provide to the project, and the time that you commit, you will be remunerated in line with the UK's National Institute for Health and Care Research (NIHR) recommended rates (for further information see https://www.nihr.ac.uk/payment-guidance-researchers-and-professionals).

How will members be selected?

We are looking to recruit people aged 18 years and above for these roles. If we receive more applications for membership of the PCUG meeting the criteria than we have spaces, we will choose members that will provide a broad experience, who are a mix of patients and caregivers across different diseases, regions and ages. If two

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applicants have similar experience or would bring similar value to the group and we need to choose just one person, we will select the member randomly.

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How can I find out more?

For any enquiries or clarifications please contact helen.wade@treat-nmd.com. To express interest in joining the PCUG, please complete this form: https://forms.cloud.microsoft/e/XbUxv2NxBw.

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