PaLaDIn

Patient Lifestyle & Disease Data Interactium

REQUEST FOR PROPOSAL:

Subcontracting a patient organisation or consortium of patient organisations to recruit a patient and caregiver user group for Project PaLaDIn.

CONTENTS

1. INTRODUCTION 3
2. PROJECT SUMMARY 3
2.1 PaLaDIn Vision 3
2.2 PaLaDIn Mission 3
2.3 The Interactium® 3
3. OVERVIEW OF THE PATIENT AND CAREGIVER USER GROUP 4
3.1 Summary 4
3.2 Role of Patient and Caregiver User Group Members 4
3.3 Expectations 5
3.4 Experience and Skills of User Group Members 6
4. SCOPE OF WORK FOR SUBCONTRACTED ORGANISATION 6
4.1 Detailed Requirements: 6
5. BUDGET 7
6. PROPOSAL REQUIREMENTS 8
7. EVALUATION CRITERIA 9
8. SELECTION PROCESS and timeline 9
8.1 Selection process 9
8.2 Timeline 10
9. FURTHER PROJECT INFORMATION 10
10. CONTACT INFORMATION 10

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.

1. INTRODUCTION

TREAT-NMD, the scientific coordinator of Project PaLaDIn, is establishing a Patient and Caregiver User Group (PCUG) for the project and therefore, seeking proposals from either:

- A European Umbrella Neuromuscular Disease (NMD) patient organisation, or
- A European Umbrella Rare Diseases patient organisation that includes neuromuscular rare disease patients, or
- A consortium of European disease-specific NMD patient organisations.

The selected organisation or consortium will be responsible for recruiting and evaluating eligible participants that meet the requirements outlined in this document for the PaLaDIn PCUG.

2. PROJECT SUMMARY

PaLaDIn (or Patient Lifestyle and Disease Data Interactium®) is a Horizon Europe project funded by the Innovative Health Initiative Call 3 (HORIZON-JU-IHI-2022-03-02). Project PaLaDIn started on 1 January 2024 and is scheduled to last 48 months.

2.1 PaLaDIn Vision

PaLaDIn will develop and implement an innovative data collection platform to accelerate the development of effective treatments and patient care, enhance healthcare decision-making and improve patient outcomes.

2.2 PaLaDIn Mission

PaLaDIn is committed to enhancing healthcare outcomes for individuals diagnosed with neuromuscular and other rare diseases through the development of 'The Interactium®,' a global, patient-centric data platform. By gathering comprehensive patient data on health status and experiences, we 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 from neuromuscular disease to benefit other rare diseases, empowering patients and advancing better healthcare outcomes.

2.3 The Interactium®

Patients and caregivers will be able to access the PaLaDIn 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

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.

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 aims 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.

3. OVERVIEW OF THE PATIENT AND CAREGIVER USER GROUP

3.1Summary

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 PaLaDIn Patient and Caregiver User Group (PCUG). Therefore, we aim 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)

3.2 Role of Patient and Caregiver User Group Members

The PCUG Members, recruited by the subcontracted organisation(s), will play a critical role in co-creation of the PaLaDIn Interactium® and other resources developed within the project, providing patient perspective and feedback on the work of the PaLaDIn project. PCUG members will be remunerated for their time and commitment in line with National Institute for Health and Care Research (NIHR) recommended rates (for further information see https://www.nihr.ac.uk/payment-guidance-researchers-and-professionals). To obtain further information, you may request a copy of the draft Terms of Reference for the PCUG.

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.

3.3 Expectations

The Patient and Caregiver User Group will be expected to:

- Provide a patient or caregiver perspective on the activities of PaLaDIn
- Support the development of the PaLaDIn Interactium® through engagement and user testing activities
- Provide input on specific tasks to facilitate successful completion of project milestones and deliverables
- Attend and participate in virtual/face-to-face Patient and Caregiver User Group kick-off meeting
- Attend and participate in virtual/face-to-face meetings/workshops when required

It is expected that the Patient and Caregiver User Group will meet virtually as required to provide support and feedback to the PaLaDIn Project. Group members will be invited to face-to-face meetings which will be held if budget and timing allows. As a minimum, the panel will meet via virtual call once every two months (bimonthly – during working hours) for 60-minute meetings. In addition to this, ad-hoc meetings may be organised to get involved in other PaLaDIn engagement activities, up to a maximum of 60 minutes every two weeks.

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

- Educational resources
- Feedback on toolkits
- 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
- Tender processes
- FAIR Components: (findable, accessible, interoperable and reusable data)
- Communications and reaching and engaging with patients

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.

3.4 Experience and Skills of User Group Members

- Be a patient, patient advocate or caregiver with a lived experience of one of the neuromuscular diseases listed above (see 3.1).
- 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 improve patient outcomes (see point 2.3 above or project-paladin.eu for further information).
- 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 formal expertise in the engagement topics. We are looking for wide range of skills and experience to ensure a broad range of perspectives are represented.

4. SCOPE OF WORK FOR SUBCONTRACTED ORGANISATION

To facilitate the establishment and recruitment for the Patient and Caregiver User Group, we are looking to subcontract with either:

- A European Umbrella NMD patient organisation, or
- A European Umbrella Rare Diseases patient organisation that includes neuromuscular rare disease patients, or
- A consortium of European disease-specific NMD patient organisations.

4.1 Detailed Requirements:

The subcontracted organisation or consortium must be able to meet the following requirements:

- Ability to recruit 5 PCUG members per disease area (listed in section 3.1), satisfying the requirements below:
    - The group can include patients, caregivers or patient advocates however patients and caregivers should constitute the majority representation within each disease area.

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.

  - Recruit participants from each disease community, aiming for a broad geographical representation across the EU whenever possible.
  - A range of disease stages which reflect the disease community.
  - Experience/interest in the project topic: harmonising or using patient data to better support research, decision making, therapeutic development and improving care standards.
  - Motivation and ability to engage and participate in the project.
  - Good level of written and spoken English.

- Ability to facilitate administrative tasks including recruitment and screening of patients.
- Facilitate initial communication of the PCUG members with TREAT-NMD.
- Subject to budget, the ability to recruit additional participants to an extended user group – comprising an additional 5 PCUG members within a specific disease area for ad-hoc disease-specific tasks, which may be requested up to twice yearly.
- Ability to provide alternative PCUG members in the event any members withdraw from the group (withdrawal will be managed by TREAT-NMD and the subcontracted organisation).
- Maintain confidentiality and declare any conflict of interests (a Conflict of Interest declaration will be required during application).
- Ability to cover these criteria for the duration of the project (scheduled end date of December 2027).
- The proposal must reflect strategic use of funding to support meaningful patient involvement.

5. BUDGET

The overall budget for recruitment, screening and ongoing administration of members of the PCUG is limited to **€30,000 in total.** (Member reimbursement costs are excluded from this total and will be administered by TREAT-NMD).

As part of the application form, please complete a cost model outlining all project-related costs and a proposed payment schedule from contract engagement through to 31st December 2027. This could include per-member recruitment costs for the PCUG, total costs for member recruitment, replacement costs for withdrawn members, and per-member costs for ad-hoc, disease-specific recruitment (if budget allows).

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.

6. PROPOSAL REQUIREMENTS

If you are a:

- European Umbrella Neuromuscular Disease patient organisation, or
- European Umbrella Rare Diseases patient organisation that includes neuromuscular rare disease patients, or
- Consortium of European disease-specific NMD patient organisations.

and are interested applying to be subcontracted to fulfil this proposal - **please complete the application form by scanning the QR code below or clicking here.** In the case of a consortium, the application form should be completed once by the lead organisation.

Please submit your application by 30th September 2025, 12pm BST.

The application form will ask for the following proposal requirements:

Organisation information:

- Name of Organisation or Consortium
- Registered address of Organisation or Consortium
- Organisation or Consortium Website Link
- Primary contact name
- Primary contact email address
- Organisation type
- Organisation overview
- For a consortium, details of the other members that have agreed to be part of the consortium

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.

Experience:

- Experience in recruiting patients and caregivers for specific projects or programmes which required focused patient and caregiver input in a 'user panel'?

Proposed approach:

- Disease communities your organisation or consortium would be able to recruit PCUG members within.
- Ability to recruit participants from each disease community, aiming for a broad geographical representation across the EU whenever possible.
- Submit a description of your approach to meet the detailed requirements included in this Request for Proposal.

Pricing structure:

- Submit a proposed cost model:
    - Organisations must submit a cost model outlining all project-related costs. Further information is detailed in section 5 above.

7. EVALUATION CRITERIA

Proposals will be evaluated based on:

- **Proposed Approach (40%)**: Approach to recruit members to the PCUG which fulfil the requirements detailed in the Request for Proposal.
- **Experience (30%):** Previous experience in recruiting patients for specific projects or programmes which required focused patient and caregiver input in a 'user panel'
- **Pricing (30%):** Competitive and transparent pricing structure.

8. SELECTION PROCESS AND TIMELINE

8.1 Selection process

Shortlisted applicants will be invited to participate in a virtual meeting to further discuss their proposal, clarify any outstanding questions, and explore alignment with project objectives. These calls will be scheduled following the evaluation of bids and will be coordinated directly with the primary contact listed in the submitted application form.

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.

8.2 Timeline

Stage	Wk1	Wk2	Wk3	Wk4	Wk5	Wk6	Wk7	Wk8	Wk9
RFP Open to Public									
Evaluation of Bids									
Virtual Call with Shortlisted Bids									
Final Decision Panel - Communication with Successful Bidders / Feedback for Unsuccessful Bids									
Contract Award and Kick off Meeting									

- **RFP Open to Public** – the RFP will be published and disseminated as far and wide as possible to the patient organisation community and umbrella organisations.
- **Evaluation of Bids** – after four weeks, submitted proposals will be reviewed by a pre-selected panel based on the requirements listed in the RFP. A shortlist of bids will be created.
- **Virtual Call with Shortlisted Bids** – a 30-minute virtual call is proposed with each shortlisted bidder to ask or answer any questions each party may have.
- **Final Decision Panel** – the pre-selected panel will make a final decision based on the RFP and Virtual Call.
- **Feedback –** feedback will be provided to all bidders after this stage, with the successful bidder being notified.
- **Contract Award** – contracting through a single service agreement.
- **Kick-off Meeting** – a kick off meeting will be setup with the successful bidder with the intention currently being this will take place in October 2025.

9. FURTHER PROJECT INFORMATION

For further information on the PaLaDIn Project, please visit the project website here.

10. CONTACT INFORMATION

For any enquiries or clarifications please contact:

dino.masic@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.