



Company:	Duchenne UK
Job Title:	Head of Patient Data
Term:	Full time/permanent
Reporting to:	Director of Research & Development
Salary range:	£60,000 - £65,000 p/a
Location:	Hybrid - subject to contract

### Our work

We are an ambitious, dynamic and impactful charity. Following their sons' diagnosis of Duchenne muscular dystrophy (DMD), Emily Reuben and Alex Johnson founded Duchenne UK (DUK) in 2012.

DMD is a devastating progressive condition diagnosed in early childhood which causes all the muscles in the body to gradually weaken. There are currently only very limited treatment options for DMD, so Emily and Alex set up DUK to change this.

Since 2012, we have raised more than £20 million to end the devastating impact of DMD. We fund ground-breaking scientific research to find effective treatments. We've developed the clinical research infrastructure to deliver DMD clinical trials in the UK. We engage industry and regulators to accelerate access to treatments. We're developing innovative assistive technologies to transform the lives of people living with DMD. And we're here to support every family affected and ensure that they receive the best possible care. We aim not only to improve quality of life but stop the disease in its tracks. We're doing it faster too, because this generation of patients can't wait.

Alex and Emily were awarded OBEs in The King's Birthday Honours List in 2023 in recognition of their services to charity and to people living with DMD. They, and the dedicated and effective team they have built at DUK, are now at the forefront of this work in the UK.

### New opportunity to join our team

We have a new opportunity to join our team and build on these achievements. We are recruiting a Head of Patient Data (HoPD), to drive and deliver the development, launch and implementation of a new DMD Patient Data Platform.

Embedded in DUK's R&D team, in the short term, the HoPD will be responsible for leading, managing and delivering this new, high-profile, strategic, and technical project, and leading on this new area of focus for the charity. In the medium to long-term, the HoPD will be responsible for developing and sustaining the DUK data strategy and delivering the DUK's data collection and data access operations, through best-in-class technology and resources to support a variety of projects across the DMD clinical research and care, R&D and market access landscape.

They will work closely with the Director of Research and Development (R&D) to ensure alignment to DUK wider R&D strategy and with the Head of Technology to leverage design and technology expertise in the team. They will also work collaboratively across the organisation to support the charity's mission to end the devastating impact of DMD.

The HoPD will report to the Director of Research and Development and in future have responsibility to line manage 1 or 2 people in their line of work.



### Job Description:

The HoPD will project manage the build and implementation of the DUK data platform and patient data collection application which will ultimately lead to a comprehensive repository of UK patient data and community resources to advance the field of medical research and care in DMD.

DUK is responsible for delivering an exemplar patient data platform, which will provide a template for country specific registries worldwide, as part of our role in an EU Horizon 2020 funded programme, Project PaLaDIn, due to kick off in December 2023. The HoPD will lead, manage and deliver the DUK work programme within PaLaDIn.

The HoPD is ideally a subject matter expert of health data collection and integration solutions, and data architecture, with experience of health data applications in R&D, market access, and in the clinical/real world setting.

They will build strong collaborations with colleagues and stakeholders at all levels, inside and outside the organisation.

In addition, the role will:

- Drive the DMD patient community engagement in all aspects of the data platform
- Build relationships with funders, partners and decision-makers;
- generate business development opportunities;
- ensure alignment to the overarching DUK strategy and organisational processes;
- ensure that our work achieves a positive impact on the lives of people living with DMD.

### Main duties and responsibilities

- Project manage the build, testing and implementation of the DUK patient data platform, including the patient interface for data collection and the data warehouse elements of the platform, taking responsibility for all aspects of project delivery including budget, delivery timeline, resources, vendor management and liaison, status update reporting and escalation of project roadblocks.
- Develop and lead the data management and governance requirements, processes, policies, compliance and structures for data, in line with DUK patient data platform strategic objectives and in consultation with internal and external stakeholders.
- Lead on the DMD community engagement activities to ensure inclusion, participation and involvement in the data platform development, maintaining stakeholder and advisory groups to ensure implementation and long-term use and adoption by the community.
- Lead on the set-up and implementation of the data governance framework, focusing on, but not limited to, the creation of data governance policies, standards, and processes.
- Lead on all data access and integration elements of projects within DUK care, education, advocacy and research programmes.
- Develop and implement engagement models for Industry, Academic and Clinical partners who want to access the data collected and held on the DUK data platform.
- Work with colleagues to identify and secure sources of income to sustain the patient data platform, including through proactive approaches to funders and partners, responding to tenders and calls for proposals, including supporting grant writing, as required.
- Develop and maintain effective relationships and networks with key relevant stakeholders, including national and local government, other national/local

agencies, trusts and foundations, service providers, and other research centres and charities.

- Keep up to date with key developments in the area of relevant data regulation and policy.
- Proactively provide advice, support and guidance to colleagues across DUK in order to improve the quality and impact of our work in data, including supporting the Director of Research and Development to develop the charity's data strategy.
- Work closely with the Director of Research and Development, other Heads within the DUK team and with the Senior Management Team.
- Contribute to the effective performance, and personal and professional development of the direct reports, through supportive line management.
- Work with the Head of Communications to communicate and promote our work and with the Senior Policy Manager to identify opportunities to influence policy and practice through our work in data.
- Contribute positive, open and collaborative working practices to the organisation.
- Support the governance of the organisation, including by producing or contributing to reports and presentations for DUK Board of Trustees, and implementation of appropriate governance as/if required in the data programme of work.

### Qualifications and experience

#### Essential qualifications & knowledge

- A relevant degree (e.g. Data Science, Data Analytics, Computer Science, IT Project Management)
- Project management qualification (e.g. PRINCE 2, AgilePM, SCRUM)
- A deep understanding of database architecture, system design, Master Data Management, data QC, cloud data warehousing, and technological solutions.
- Knowledge of data regulations including GDPR and PHI (Personal Health Information)

#### Essential experience & expertise

- Proven track record of successfully project managing and delivering multi-vendor data projects, using industry standard project management techniques e.g. Agile, Sprint
- Experience of implementing data structures, including the use of data acquisition and data cleansing tools
- Experience of data integration and interoperability (API driven data product)
- Contracting and finance management experience
- Data management and governance experience including strategy around Subject Access Request (SAR) and Freedom of Information (FOI)
- Experience of master data and metadata management
- Experience of liaising with senior individuals in a variety of organisations with an ability to create favourable working relationships
- Proven track record in building strong relationships with government, vendors, partners and funders
- Experience in creating and implementing data collection services, including but not limited to: connection to 3<sup>rd</sup> party services, intake data, QC, deduplicate, normalise, structure, store, make available for downstream services and partners

#### Desirable

- Knowledge of the UK health data ecosystem, including NHS data systems and infrastructure
- Experience with cloud data stack (AWS, Azure or GCP)
- Experience of working with health/patient data (including EMIS and SystemOne)
- Experience of implementing data collection apps
- Experience of working with clinical stakeholders e.g. consultants, patient advocacy groups

- Knowledge of the charity sector

#### Key skills for the role

- Excellent project management skills, including time, resource, budget and vendor management
- Attention to detail and record keeping
- Strong people management skills, including developing and motivating direct reports, and forging excellent working relationships with colleagues, vendors and stakeholders
- Ability to work under own initiative with a proactive approach to problem solving.
- Self-motivated, flexible and enthusiastic team player who can also work independently contributing to the development of a positive, can-do culture
- Ability to work and deliver under pressure to tight deadlines
- Ability to review and critically appraise information, data and literature
- Strong written and verbal communication skills with the ability to convey complex ideas and information to a range of audiences, stakeholders, funders and partners
- Confidence and diplomacy when dealing with stakeholders with diverse levels of experience and seniority

#### Other Requirements

- Occasional working outside of office hours for key events and activities
- Occasional travel may be required
- Undertaking any other duties which are required and are commensurate with the role of HoDP

#### Working for Duchenne UK

We are a friendly, energetic, and determined team. As we are led by two parents of boys who live with DMD, our team has a very strong feeling of contribution to our mission.

We prioritise team building and wellness through an annual offsite Team Away Day and an annual offsite Wellness Day, alongside social activity throughout the year.

We operate a hybrid working week, to balance our team-based culture with a positive home-life. In the summer months of July and August, staff benefit from 'Summer Fridays', allowing them half days on Fridays (pro rata'd for part time staff) to enjoy the long summer weekends.

Sound like the job for you? We'd love to hear from you:

#### Benefits

- 25 days of annual leave + 8 days of public holidays (both pro rata)
- Summer Fridays – half days on Fridays in July and August (pro rata)
- Flexible working policy
- Hybrid working
- Standard Employer Pensions contributions after 3 months
- Team wellness day and team away day
- Training and development opportunities

#### Terms and conditions

The appointment is subject to satisfactory references and an initial six-month period of probation, during which performance will be regularly reviewed.

Relevant training will be provided during induction as well as opportunities to develop your career through experience of different aspects of the charity's work and working with colleagues on new initiatives.

The organisation's hybrid working policy is at the discretion of the line-manager during the first three months of employment, to support the induction process.

#### Applying for this job

Please send us a copy of your CV. In addition, please answer the following questions, with a maximum of 300 words per question. You can send us a short film with your answers if you prefer or let us know if you would like to give us this information in a different way.

1. Please tell us why you would like to work for DUK.
2. In the job description, we have highlighted a range of experiences and skills we think we need. Please describe how you have demonstrated these in your career to date. Please give us practical examples. It's ok to use experiences from outside of paid work, including experiences you may have had in your personal life.
3. If you think you have other qualities, we have not mentioned but which you think suit this role, please let us know. We want to know some of the things you have done and the experiences you've had, and what you think they have taught you.
4. Tell us one thing that really excites you about this role. If you would like to discuss the role, please contact [recruitment@duchenneuk.org](mailto:recruitment@duchenneuk.org)
5. Please email your applications to [recruitment@duchenneuk.org](mailto:recruitment@duchenneuk.org)

#### Timetable

Deadline for applications	
Interviews	Week commencing 15 <sup>th</sup> / 22 <sup>nd</sup> January 2024
Follow up interview if required	TBC
Decision made & successful candidate notified	By mid February 2024