昆山杜克大学校企协同创新平台_挑战项目详情

合作方信息			
机构名称：	FSHD 青年路社区 & 天工开物开源基金会		
机构类型：	NPO		
官网 / 官方账号链接：			
联系人：	庄表伟、艾力亚尔·艾克排尔		
项目信息			
项目类别：	科技创新类		
预期开启时间	2026 年 2 月	预计结束时间	长期项目

机构背景：

FSHD 青年路社区是由面肩肱型肌营养不良（FSHD）患者自发主导的全国性公益社群。这是一种遗传性肌肉萎缩疾病，属于进行性肌营养不良的常见类型之一，也是第三大骨骼肌遗传病，全球发病率约为 1/20000，患者总数超 87 万人。该病为常染色体显性遗传（95%），其中 20%-30%的患者为新生突变，无家族遗传史。发病年龄跨度较大，可从婴儿期到成年期，常见于 20-40 岁，也有不少在 10-20 岁起病。典型症状为面部、肩部及上臂肌肉逐渐无力和萎缩，影响闭眼、抬眉、举臂等动作，部分患者会累及躯干或下肢肌肉，影响日常活动。患者病情差异较大，约 20%最终需使用轮椅，但疾病进展通常缓慢，极少影响心脏或呼吸系统，大部分患者可拥有正常寿命。目前尚无根治或延缓疾病进展的药物，康复训练等方式可帮助维持肌肉功能和生活质量。自 2023 年成立已覆盖 1000 + 患者家庭，秉持“共建、共治、共享”理念，借助 AI 客服等技术，为病友提供紧密情感陪伴与经验分享。开展线下赋能会、康复营，运营患者互助小组，并通过 AI 助力举办科普活动、参与国际学术会议。未来将打造患者数据平台，扩大覆盖范围，深化科研合作，提升社会对 FSHD 的认知与支持 。

天工开物开源基金会于 2023 年 3 月登记成立，由清华大学、华中科技大学、重庆大学、中冶赛迪、中国信科、中科院等知名高校和企业联合发起，致力于推动中国开源产业公益事业的非营利性独立法人机构。天工开物开源基金会本着“开放、务实、专业、创新”的发展理念，推动开源技术赋能国产工业软件和制造业数字化转型发展；遵循共建、共治、共享原则，系统性打造开源开放框架，搭建企业、高校开源社区，提升软件行业及应用单位的协作效率，赋能千行百业。目前，基金会业务范围主要包括募集资金、专项资助宣传推广、教育培训、学术交流、校企合作、开源生态建设、咨询服务等业务。

项目概述：

本项目将基于已有的学生项目进度，持续聚焦于科技赋能健康议题，联合了一个以支持罕见病患者为核心的开源社区，旨在推动疾病信息的透明、患者支持的多样化以及数字工具的共创与迭代。此次项目将围绕面肩肱型肌营养不良症（FSHD）这一罕见病展开，参与者将在来自业界与研究领域的导师指导下，深入了解 FSHD 患者社区当前面临的具体需求，并基于现有开源平台，共同开发一至两个全新的功能模块。

该项目将采用以用户需求为导向的协作开发模式。具体可能涉及的方向包括但不限于：

- 症状记录与跟踪功能（如肌力、疲劳程度、生活影响）
- 医疗资源或患者案例共享机制
- 面向照护者的任务管理或提醒系统
- 增强可访问性的用户界面优化
- 数据可视化或统计分析功能支持患者更好地掌握自身病情
- 用户匿名化数据收集模块以供研究使用

期间团队将通过调研、原型设计、用户测试及迭代开发等阶段完成具体产品开发，并在期末向社区及合作方进行成果展示。该项目不仅提供了实践软件开发与人本设计的方法路径，也鼓励参与者通过技术助力公共健康议题，真正实现“以人为本”的社会创新。

支持与资源：

1. 任务与项目资源：提供完整的任务信息，包括项目背景资料、开发需求说明以及预期成果。
2. 技术与平台支持：提供必要的开发平台、代码库访问权限、API 接口及相关技术文档，确保学生能够顺利进行项目开发。
3. 导师或指导支持：安排项目负责人或技术/运营导师，定期进行答疑、反馈与进度指导，帮助学生解决开发中遇到的技术或协作问题。
4. 项目评估与反馈：提供阶段性评估与反馈，包括项目可行性、用户体验、技术实现等方面的指导，帮助学生优化成果。
5. 合作交流渠道：为学生团队与外部项目组搭建沟通渠道，包括线上会议、协作工具及必要的对接支持。

其他说明：

DKU Co-Innovate Platform_Challenge Information

Partner Information			
Organization Name:	FSHD Qingnian Road Community & The Chance Foundation		
Organization Type:	NPO		
Website / Official Account Link:	https://info.xiao-x-bao.com.cn		
Contact Person:	Biaowei Zhuang, Ailiyier AikepaiEr		
Project Information			
Project Category:	Technology Innovation Project		
Expected Start Date	February 2026	Expected End Date	Long-term Collaboration

Organization Background:

FSHD Qingnian Road Community is a national public welfare group spontaneously organized and led by people with facioscapulohumeral muscular dystrophy (FSHD). FSHD is a genetic muscle-wasting disorder and one of the most common types of progressive muscular dystrophy. It is the third most prevalent hereditary skeletal muscle disease worldwide, with an incidence of about 1 in 20,000 and more than 870,000 patients globally. The condition is autosomal dominant in about 95% of cases, with 20%–30% arising from new mutations without a family history. Onset can occur at any age—from infancy to adulthood—though it is most common between ages 20 and 40, and not uncommon between ages 10 and 20. Typical symptoms include gradual weakness and atrophy of the facial, shoulder, and upper arm muscles, affecting actions such as closing the eyes, raising the eyebrows, and lifting the arms. In some cases, the trunk or lower limb muscles may also be involved, impacting daily activities. Disease severity varies greatly: around 20% of patients eventually require a wheelchair. However, progression is usually slow, the heart and respiratory systems are rarely affected, and most patients have a normal lifespan.

Since its establishment in 2023, the community has reached over 1,000 patient families. Guided by the principles of “co-building, co-governance, and sharing,” and leveraging technologies such as AI-powered support, it provides close emotional companionship and experience-sharing for patients. It organizes offline empowerment meetings, rehabilitation camps, and patient mutual-aid groups, and uses AI to support science communication activities and participation in international academic conferences.

Looking ahead, the community aims to build a patient data platform, expand its reach, deepen research collaborations, and enhance public awareness and support for FSHD.

The Chance Foundation (also known as Corporation of Human @nd Nature Create Everything) was officially registered in March 2023. Jointly initiated by renowned universities and enterprises including Tsinghua University, Huazhong University of Science and Technology, Chongqing University, MCC CIE, China Information and Communication Technology Group (CICT), and the Chinese Academy of Sciences, it is a non-profit and independent legal entity dedicated to advancing China's open-source industry for the public good.

Adhering to the development philosophy of "Openness, Pragmatism, Professionalism, and Innovation", the Foundation promotes open-source technologies to empower domestic industrial software and drive the digital transformation of the manufacturing industry. Following the principles of co-building, co-governance, and sharing, it systematically develops open-source frameworks, builds open-source communities across enterprises and universities, enhances collaboration efficiency within the software industry and user organizations, and empowers a wide range of sectors. Currently, the Foundation's main areas of work include fundraising, targeted sponsorship for promotion, education and training, academic exchange, university–enterprise cooperation, open-source ecosystem development, and consulting services.

Project Overview:

This project focuses on leveraging technology to address health-related challenges, partnering with an open-source community dedicated to supporting rare disease patients. The goal is to promote transparency in disease information, diversify patient support, and facilitate the co-creation and iterative development of digital tools. The project centers on Facioscapulohumeral Muscular Dystrophy (FSHD), a rare disease. Under the guidance of mentors from industry and research, participants will gain an in-depth understanding of the specific needs faced by the FSHD patient community and collaboratively develop one or two new functional modules based on an existing open-source platform.

The project will adopt a user-needs-driven collaborative development model. Potential focus areas include, but are not limited to:

- Symptom tracking and logging (e.g., muscle strength, fatigue levels, impact on daily life)
- Medical resource or patient case-sharing mechanisms
- Task management or reminder systems for caregivers
- Accessibility-focused user interface optimizations
- Data visualization or statistical analysis tools to help patients better understand their condition
- Anonymized data collection modules for research purposes

The team will progress through stages such as research, prototyping, user testing, and iterative development to complete the product. A final presentation will be delivered to the community and partners at the end of the term. This project not only provides hands-on experience in software development and human-centered design but also encourages participants to use technology to drive social innovation in public health, truly embodying the principle of "people-first" solutions.

Support & Resources:

1. Tasks & project resources: Provide the list of projects with details, including project background materials, development requirement descriptions, and expected deliverables.
2. Technical & platform support: Provide necessary development platforms, access to code repositories, API interfaces, and technical documentation to ensure smooth development.
3. Mentor/coaching support: Arrange project owners or technical/operations mentors for regular Q&A, feedback, and progress coaching to help resolve technical or collaboration issues.
4. Project evaluation & feedback: Provide staged evaluations and feedback (e.g., feasibility, user experience, technical implementation) to help students optimize outcomes.
5. • Collaboration channels: Set up communication channels between student teams and external project teams, including online meetings, collaboration tools, and necessary liaison support.

Additional Notes: