# RAREsummit21 Innovation challenge: rare disease pitching pack

Last year at RAREfest20, Eastern AHSN and the Cambridge Rare Disease Network (CRDN) launched a survey to engage patients and carers from the rare diseases community to share their insight and enable us to develop a set of challenges which we then put to the innovation community to find and develop solutions.

## Our challenge statements

Following analysis of the survey responses, we developed the following challenges, which we put to the innovation community through the *Innovation challenge: rare diseases*.

- How might we use digital technology or AI to improve access and availability of clear, reliable health information about rare diseases for patients, family members, healthcare professionals and/or members of the public?
- How might we use AI and digital technology to improve coordination of care for people living with rare diseases?
- How might we use digital technology to maintain wellbeing and reduce mental fatigue for people living with rare diseases?

## Shortlisted innovations

For RAREsummit21, we invited innovators to share their solutions to our challenge statements and submit them to our Innovation challenge: rare diseases. All submissions were judged and scored by a panel of experts, and the 5 highest scoring innovations have been invited to pitch at RAREsummit21.

This pack provides more information supplied by the innovators.

- Asclepius Digital
- Medwise.ai
- Noink by DSST
- Thriving.ai
- Vitaly Collaborative decision making by Parsek Group

*This pitch pack is intended to give an overview of each innovation and the intended potential for patient impact. Whilst we encourage referencing on any claims made by innovators, Eastern AHSN has not fact-checked submissions for accuracy.*

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| **Innovation** | Ascelpius Digital | **Organisation** | Sundown Solutions Ltd |
| **Unmet need that this innovation addresses** | Rare diseases impact hundreds of millions of families around the world. Currently, no overarching model exists for uniform standards of care and diagnosis. It can take years for patients to receive a correct diagnosis for rare diseases. Even once this diagnosis has been made then, care protocols are often hard to find, amplifying the pain and anguish that families already face in their challenging medical journeys. We are looking to simplify, streamline and ultimately transform this journey through the innovative combination of service offerings which exist within Ascelpius Digital.<br><br>Through the provision of a secure and focused community for patients, patients' families, and health care professionals (HCP's) we are building a single new ecosystem which together will improve the outcomes for all concerned. "The whole is greater than the sum of the parts" and this community will collaborate as a collegiate motivated body.<br><br>Ascelpius Digital is an innovation which will deliver tangible benefits to patients, family members and all health care professionals (HCP's) living with, diagnosing or treating rare diseases. It will result in an improvement in the diagnosis and treatment of these rare and challenging diseases.<br><br>We aim to expedite early diagnoses of rare diseases in paediatric cases which will improve outcomes for patients and avoid current issues with early intervention and access to diagnosis and treatments.<br><br>There are several barriers hindering early rare disease diagnoses for children including:<br><br>• HCPs/PCPs often lack the right pre-screening tools, resulting in a significant time/cost burden for patients and parents<br><br>• And even when a child is diagnosed with a rare disease, communication and collaboration between HCPs, specialists, children, and parents can be challenging. | | |
| **Description of innovation and how it addresses the unmet need** | Ascelpius Digital is made up of 4 component parts:<br><br>• App<br>• Portal<br>• Wiki<br>• YellowBracelet | | |

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| | The App enables access to specialist rare disease consultants and remote diagnosis for patients who have been referred for consultation by a specialist.<br><br>The Portal acts as real-time repository and coordination hub which reduces the barriers for researchers, clinicians, and patients in determining appropriate diagnosis and clinical care for rare disease patients. Critically this includes ongoing input from patients and families and an open "wiki" format for near real-time updates from vetted contributors to enable access to the latest, real world data and direct engagement in the provision of care.<br><br>The Wiki includes ongoing input from patients and families and an open "wiki" format for near real-time updates from vetted contributors to enable access to the latest, real-world data and direct engagement in the provision of care.<br><br>YellowBracelet is the digital data broker or the secure 'glue' that aligns technology, data and people. It enables secure and immediate access to pertinent health care records via a QR code from any enabling secure access from any approved smartphone or tablet device for authorised users. This delivers a far more efficient method of engaging with HCP's, patients and their families. It enables seamless access to Health Care Records, with full integration to NHS Care Plans and GP Records. |
| **Expected benefits** | **<u>Patient benefits:</u>**<br><br>From a patient perspective the key benefit is helping to realise early diagnosis of disease through improved collaboration and consultation with specialists across the UK / globe.<br><br>Just as Wikipedia revolutionized how we think of the encyclopaedia, the developments and tooling we have created will help harness technology to revolutionize access to care standards for rare disease globally.<br><br>The primary benefit expected will be to help patients get faster access to the optimised treatment for their particular rare disease diagnosis. This is critical in helping them manage their care in partnership with the HCP providers to achieve a better health outcome.<br><br>**<u>Healthcare system benefits:</u>**<br><br>By providing access to all interested parties the solution will democratise data and remove data silos. This will empower patients to make decisions and equip them and their families to have informed conversations with HCP's who equally can easily collaborate with their colleagues and peers across organisations and geographies. |
| **Market research undertaken to see if this fits** | Our research both at a National Level, with individual Trusts and across the health and social care ecosystem has validated that the solution is well aligned with NHS priorities and in particular:<br><br>- Expanding primary care capacity to improve access, local health outcomes and address health inequalities |

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| **with any NHS priorities** | - Transforming community and urgent and emergency care to prevent inappropriate attendance at emergency departments (ED), improve timely admission to hospital for ED patients and reduce length of stay<br>- Working collaboratively across systems to deliver on these priorities<br><br>Feedback at both a national and local level continues to be positive further demonstrating the need for the solutions Sundown are bringing to market and our approach to simplifying the sharing of information, access to data, the coordination of resources and effective communication.<br><br>We have already successfully deployed one element of the solution for the elderly and/or frail communities in both NENE and BLMK. The Yellow Bracelet component is delivering tangible benefits in the quality of care and the cohesive provision of care packages to these communities, and this will continue to increase as the usage numbers grow through the rollout programme.<br><br>The other 2 elements focused on Rare Disease have been rolled out to the USA market, and we are now in phase 3 of deployment / expansion. |
| **How is your innovation different to existing technologies / products / services?** | This is a unique innovation in how it aligns the patient and HCP into a single community focused on the diagnosis and treatment of rare diseases. There is nothing else like this anywhere outside of the offering we delivered to RDI / NORD in the US.<br><br>We can drive the democratisation of access to the right information, the right support and the right treatment when they need it irrespective of who they are or where they live. |
| **Future plans / spread of adoption / scalability** | Further adoption and utilisation across the US with a view to in parallel integrating with EURORDIS. This will enable Ascelpius to become the single global platform of choice, supported by the World Health Organisation, allowing all patients no matter their geography or their socio-economic position the same access to information, diagnosis, treatment and support. |
| **External Links and contact email** | Tony Boyle: tony@sundownsolutions.com |

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| **Innovation** | Medwise | **Organisation** | Medwise AI Ltd |
| **Unmet need that this innovation addresses** | Information regarding Rare diseases is difficult to find and stored in siloed locations. Disseminating, searching and accessing the latest best practices can be difficult for clinicians and healthcare professionals caring for patients with rare diseases. | | |
| **Description of innovation and how it addresses the unmet need** | Medwise uses AI powered search to allow clinicians to instantly access answers to their clinical questions. Advanced question and answer algorithms and natural language processing models means that previously difficult to find, long form documents are instantly accessible and searchable by clinicians. Medwise can act as a central repository for information, allowing quick and efficient dissemination of best practice information amongst the rare disease community. | | |
| **Expected benefits** | **Patient benefits:**<br><br>Patients receive the latest best practices from their clinicians through the collective shared knowledge of the rare diseases community.<br><br>**Healthcare system benefits:**<br><br>Improved clinical decision making, both in terms of evidence base and time saved in searching for information. | | |
| **Market research undertaken to see if this fits with any NHS priorities** | Our solution addresses one of the key priorities set out in the NHS Long Term Plan, namely the use of decision support and artificial intelligence (AI) to help clinicians in applying best practice, eliminate unwarranted variation across the whole pathway of care, and the use of digital technology to deliver high quality specialist care more efficiently. | | |
| **How is your innovation different to existing technologies / products / services?** | Our AI-powered search allows users to retrieve concise answers from complex, long-form documents. This is different to websites that have poor search functionality and are difficult to navigate, or google which may include unprofessional and unverified content as results. | | |
| **Future plans / spread of adoption / scalability** | Our main product is a freely available general medical information platform aimed at GPs and other clinicians working in primary care. We are working with integrated care systems to integrate locality-specific guidelines, referral pathways and information about services onto our platform to support their clinicians. Our | | |

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| | near-term goal is to expand to include secondary care specialities and rare diseases. |
| **External Links and contact email** | Dr. Keith Tsui - CEO - keith@medwise.ai |

**NOINK**

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| **Innovation** | Real world data capture for Rare Disease Families | **Organisation** | DSST Limited<br><br>(Makers of the noink platform) |
| **Unmet need**<br><br>**that this innovation addresses** | Real world patient data has clinical and scientific value. Often overlooked in patient care. DSST's noink platform allows rare disease patients to capture and use their data to:<br><br>• Know how their condition affects them personally (via quantified self, extreme localisation and customisation)<br>• Get contextual, educational information (signposting and self-help)<br>• Have a more effective relationship with their clinician (improved consults - even remotely)<br>• Further clinical research (by making their data available to industry and researchers | | |
| **Description of innovation and how it addresses the unmet need** | Rare disease patients suffer for a lack of fit for purpose technology to help their conditions. Most technology is informational in scope. Specific technology for rare disease families is ad-hoc if it exists at all. By abstracting underlying condition from data capture, noink can work for ALL rare conditions. This gives rare disease families the power to help themselves with their objective data. | | |
| **Expected benefits** | **<u>Patient benefits:</u>**<br><br>• Improved self-management<br>• Better informed clinical consults<br>• Educational resources to improve patient knowledge<br>• Utility to save families time and stay organised<br><br>**<u>Healthcare system benefits:</u>**<br><br>• Efficiencies with chronic illness care through more effective consults<br>• Ability to remote monitor a condition with objective data<br>• A repository of real world data to further clinical practice, research and industry studies | | |
| **Market research undertaken to see if this fits with any NHS priorities** | The noink platform is already used in a capacity within the NHS for complex care cases. We have worked with some rare disease organisations across the globe to make noink an indispensable healthcare tool for this overlooked condition area. | | |

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| | DSST has started our NHS interaction journey via extensive use of their data API for patient information and signposting.<br><br>We have commenced our IM1 journey with the NHS for Primary care record integration. |
| **How is your innovation different to existing technologies / products / services?** | DSST have concentrated on solving the larger data capture problem for ALL rare conditions rather than a single condition focus. Uniquely noink is:<br><br>• Multi user (reflecting the reality of rare disease caregiving)<br>• Multi-condition – addressing co-morbidities and seeing the patient as more than a set of symptoms<br>• Multi-lingual – removing language barriers to healthcare and greatly increasing cohort size for studies<br>• Provides contextual signposting and informational content from trusted sources to improve patient self-care.<br>• We provide utility to patient families which improves adherence |
| **Future plans / spread of adoption / scalability** | We seek engagement from rare disease organisations and subject matter experts to on-board even more rare conditions and get it into the hands of rare disease families to improve their health and contribute to clinical and scientific research. The technology is built with battle tested infrastructure that scales horizontally across all conditions and user demand. |
| **External Links and contact email** | E: liam@noink.me<br><br>W: www.noink.me<br><br>https://www.noink.me/cws/news/mkd_press.php<br><br>https://www.noink.me/cws/news/<br><br>https://youtu.be/IDFsOgJnVkg |

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| **Innovation** | Thriving.ai | **Organisation** | Thriving Ai Limited |
| **Unmet need**<br><br>**that this innovation addresses** | • Care for people with rare diseases **requires coordination, communication and monitoring** of both health & social care.<br>• Stakeholders need **access to information and resources** to ease the fear of the unknown and provide peace of mind.<br>• Dealing with a rare disease has inherent **stress and anxiety** therefore connection with care providers, an experienced community is key.<br>• Receiving **quality inspirational content** can transform life.<br>• **Data** is a key issue in understanding these diseases. Access to data from all perspectives helps build an understanding of the impact of rare diseases.<br>• **Historical lack of investment** and adoption of new technologies in caregiving.<br><br>***Thriving.ai*** is an app that brings it all together for a better caregiving & receiving experience. | | |
| **Description of innovation and how it addresses the unmet need** | Thriving is an app that integrates health & social care, formal & informal care around a Thriver, the person being cared for and is underpinned by machine learning and AI capabilities. The application enables the person being cared for to **check in, report how they are feeling, interact & communicate with all members of their circle of care, access special interest content as well as relevant medical content related to their needs**. **The platform collects tagged data to learn about the user so that the app can provide positive behavioural prompts to help with mood, pain, and engagement.**<br><br>The data dashboard collates & learns from multiple pieces of information to suggests proactive behaviours through custom prompts & provides insights. The clinical setting for the application can be in transition from hospital to home or regular use in a community setting. **An API is available for EMR & other integrations.** | | |
| **Expected benefits** | **Patient benefits:**<br><br>-**Patients/Family are at the centre of the solution** & are part of the solution.<br><br>-**Save time and effort** by updating your entire circle of care in one go for quick decision making and effective delivery of care<br><br>-**Check-ins allow the Thriver to share how they are feeling. It provides a sense of security and confidence to be independent**, whilst knowing someone is looking out for them (e.g.: if they miss a check-in, someone will be alerted)<br><br>-**Positive affirmations and motivational responses help foster positive mindsets**<br><br>- Ability to interact with the circle of care, **increases Thriver engagement**<br><br>-Monitoring mood over time helps focus in on smaller issues thereby reduces risks repeated hospitalization<br><br>-**In-app communications** makes connecting with the circle of care easy<br><br>-**Sharing care with a group reduces the care burden** on a single person | | |

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| | -**Data capture & analysis provides insights for improved care & content**<br><br>- **Access to information, care and support reducing their stress, mental fatigue**, and worry.<br><br>**<u>Healthcare system benefits:</u>**<br><br>Key issues are a **limited understanding of the diseases**, **lack of patient & caregiver data,** the **challenge & cost of treating small disease populations** & lack of coordinated care. The number of people living with rare disease globally is 350 M and the disease burden is high.<br><br>Thriving.ai helps by:<br><br>- Delivering **integrated, holistic care**<br><br>- **Reducing administrative time** for stakeholders involved (time = money)<br><br>- Access to all tracking and **data records in one place**<br><br>- **Check-in evaluations and mapping** allow health care providers to plan and optimize home visits.<br><br>- **Improved staff retention** through reducing workload for carers.<br><br>-**Automating administrative tasks** (e.g.: routing) allows care experts to focus on care delivery.<br><br>-**Notifications** give Thrivers & Family **peace of mind** knowing when professionals are on their way.<br><br>**Family members can care from work allowing them to remain financially resilient.**<br><br>Employers who lose 1in 3 staff with caregiving duties can **retain staff & save costs. (Massachusetts Caregiver Coalition 2020)**<br><br>**ML/AI data** for preventative care & cost savings in monetary terms.<br><br>Often hospitalization or institutionalization is sought when the care burden cannot be well managed. |
| **Market research undertaken to see if this fits with any NHS priorities** | We have undertaken desk research, spoken with CCG's and upcoming Integrated Care Services. It is a priority post pandemic to ensure that better care is supported in the community & that it is coordinated for better operational & medical outcomes.(https://www.england.nhs.uk/wp-content/uploads/2021/02/C1127-integrated-care-systems-next-steps-letter.pdf) The World Health Organisation (WHO) recognizes the importance of integrated care & recently developed a '*Framework on integrated people-centered health services*' calling for fundamental change in the funding, management, & delivery of health services. We have **two letters of support for the use & testing of our solution in the NHS.** Results of our AARP surveys; 145 Thrivers receiving care – **38% said that the App, was very relevant** or relevant and 263 carer' surveyed **63% said that it was very relevant** or relevant. Payer interviews: **4/5 budget holders will pay** for this service if we demonstrate adoption |
| **How is your innovation different to existing technologies /** | Our solution is different from existing technologies in that:<br><br>a.) The patient & family carer are at the centre of the solution. **Patient centric** |

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| **products / services?** | b.) We create an **integrated care model** across medical, social, formal, and informal care sectors<br><br>c.) Bring together core functionalities in a **Super App for convenience**, time saving, and unfragmented care.<br><br>d.) **ML & AI to learn & predict better outcomes**<br><br>e.) Enhance patient care and interaction, engage care providers, use intelligent prompted responses help create behavioural change.<br><br>f.) **Data insights** drive real-time data driven decision-making.<br><br>g.) Integrate communication and **telemedicine functionality** to enable instant contact, support, and care updates.<br><br>h.) Includes product integrations **for food (nutrition), exercise, daily aids, social engagement, transportation, and skill-swap** with others to learn and share<br><br>i.) Our roadmap will integrate IOT/Sensors/Wearables for independent living. |
| **Future plans / spread of adoption / scalability** | - Upcoming pilots with 3 parties (social housing, an ICS group, and a home health care delivery partner)<br><br>- In discussion with partners focused on remote patient monitoring |
| **External Links and contact email** | Website: https://www.thriving.ai / Email: shain@thriving.ai |

**PARSEK**

# AI-supported Multidisciplinary Team Meetings (MDTs) providing more accurate diagnosis and shorter time to decision for patients with rare cancers

| **Innovation** | **AI-supported regional MDTs** | **Organisation** | Parsek Information Technologies |
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| **Unmet need**<br><br>**that this innovation addresses** | Diagnostics of patients with rare cancers such as Malignant Mesothelioma (MM) is increasingly hampered. The experts are limited, and not all local medical organisations can offer diagnostic services of the same quality and multidisciplinary expertise. In addition, key specialists are often dislocated and sharing information takes much time with annoying delays for the patient. Furthermore, population screening programmes are usually not in place for rare diseases, so most cases are discovered in an advanced stage.<br><br>Rapidly evolving diagnostic and treatment options have made Multidisciplinary Team Meetings (MDTs) necessary to join the best regional experts to reduce variations in care for all cancer patients, including MM. However, performing them is labour-intensive, time-consuming, and error-prone. So is the detection of minor abnormalities in the area of lungs where overworked radiologists need to provide precise diagnostics, leading to sub-optimal health outcomes. | | |
| **Description of innovation and how it addresses the unmet need** | Vitaly is a high-quality web-based application for professional teams involved in the regional MDTs that enhances how multiple experts collaborate and make informed decisions regardless of their location. It provides a complete and up-to-date picture of the patient data for all the professionals involved, turning complicated, laborious, and often non-transparent situations into a simple, efficient, and time-saving framework. Enhanced by AI-assisted radiology material review indicating the abnormalities around the lungs, it helps radiologists provide more precise expertise, faster.<br><br>As recommended by the British Thoracic Society (BTS) Guidelines, our MDTs is fully virtual, set on an interoperable enterprise-level software solution to avoid inefficient governance, patient rescheduling, and provide time- and cost-effective cross-organisational collaboration. Our MDT solution, implemented for Urology cancer MDTs in the Netherlands, successfully addresses the major barriers of multi-institutional collaboration, to minimising costly administrative efforts, improve clinical utilisation, support high-quality decision-making and shorten prolonged decision cycles. | | |

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| **Expected benefits** | **<u>Patient benefits:</u>**<br><br>▪ Improved health outcomes and quality of life<br>▪ Faster time to treatment recommendation<br>▪ More accurate diagnosis (also enabled with AI support)<br>▪ Better care option regardless of the location<br>▪ Increased trust in the decision-making process<br><br>**<u>Healthcare system benefits:</u>**<br><br>▪ Reduced drain on scarce human resources due to digital information exchange, streamlined workflows and remote presence options;<br>▪ Faster and more precise diagnostic results (enabled by AI support)<br>▪ Reduced need to travel due to remote presence option<br>▪ Better clinical utilisation by minimising costly administrative efforts,<br>▪ More accurate decision-making and shortening prolonged decision cycles |
| **Market research undertaken to see if this fits with any NHS priorities** | **NHS England and NHS improvement**: *»MDT Streamlining should support the drive for personalisation and ensure that shared decision-making in care, and personalised care and support planning, are routine for all patients.«*<br><br>**Cancer Research UK:** *"Meeting patients' needs: improving the effectiveness of multidisciplinary team meetings in cancer services highlights the need to refresh the format of multidisciplinary team meetings. The report contains several UK-wide recommendations, aiming to streamline and optimise MDT meetings in order to better meet the needs of patients today and in the future."*<br><br>**The UK government Department of Health and Social care** has stated in January 2021 to *»build upon recent advances in diagnostic technologies, most notably in genomics and data analysis, to help patients receive a final diagnosis faster and reduce the 'diagnostic odyssey' faced by so many. /.../ As many rare diseases often cut across multiple clinical specialities and care providers, we will also work to remove unnecessary barriers to improve the coordination of care throughout the patient journey and utilise new technology and digital tools /.../. «* |
| **How is your innovation different to existing technologies / products / services?** | Compared to other digital MDT solutions:<br><br>• designed to connect a variety of specialists and organisations regardless of the size and location<br>• agnostic solution that can scale to different care areas and settings<br>• interoperable, smooth integration with existing HIE exchange systems<br>• AI-enabled, meaning that efforts and human error are reduced, and diagnostics go beyond what is possible for us humans to gain insights for prognosis and treatment recommendations.<br>• proven outcomes in terms of cost efficiency and quality of care |

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| **Future plans / spread of adoption / scalability** | • **Solution implementation and Configuration**: a virtual AI-supported MDT solution will be set up to enable clinical use to improve clinical practice for all patients with MM and scaled across the region. If recognised as successful, it could scale to cover overall lung cancer MDTs.<br>• **Clinical trial**: aiming to assess how cross-organisational discussions and management of all patients with MM that proceeds equally across the region affects health outcomes.<br>• **Patient and Public Involvement**: usability research to achieve wider user adoption & improved user experience.<br>• **Impact study / Health economics**: research to provide a clear overview of patient outcomes and benefits. Analysis of the demonstrated optimisations of time and resources saved. |
| **External Links and contact email** | • **Website Parsek**: www.parsek.com , Contact: zan.virtnik@parsek.com<br>• **Website Aidence (AI partner):** www.aidence.com<br>• **Web page Vitaly Collaborative decision making solution:** https://parsek.com/solution/collaborative-decision-making<br>• **Case study**: The power of collaborative decision-making in multidisciplinary approach |

**Ends**