



Digital

Social Care Digital Innovation Programme



**Wirral's Project:
Bio-metric Assessment of
Autism Sensory Processing
(BAASP)**



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Discovery Phase Review [40%]

Problem to solve (Was this reframed during the discovery phase?) [2%]:

- The Social Care Digital Innovation Programme (SCDIP) supports the adult social care sector to use digital technology to respond to challenges in local areas. The SCDIP is funded by NHS Digital and managed through the Local Government Association (LGA). The Wirral Project is intended to enhance direct practice, improve information sharing and enable integration through working with a small group of Adults to conduct Bio-metric Assessment of Autism Sensory Processing (BAASP).
- NHS figures from 2015 show that as many as 24,000 people with learning disabilities or autism were at risk of admission to hospital, revealing the large number of people at crisis point at any one time. Later figures, from autumn 2017, show that a third of people with autism in hospital had been there for two years or more. Many staff do not have the expertise to help support this client group.
- Many individuals with autism experience sensory processing difficulties, whereby they are either hyper- or hypo-sensitive to light, sound, taste, touch, temperature, smell, and/or own spatial awareness. These processing difficulties can cause significant distress, physiological arousal, and heightened anxiety that lead to major behavioural events including self-harm, harm to others, damage to property, tantrums, meltdowns, and/or elopement.
- People with autism may be unable to verbalise anxiety/distress. Frequent crisis admission cycles often end with pharmaceutical intervention; however, the root cause of crisis is rarely identified, and a lasting reduction of symptoms is not achieved. The therapeutic benefit of medication diminishes with time and negative side effects increase with the duration of their use.
- The Wirral Project is providing an intervention to people with complex autism and learning difficulties who are unable to verbalise anxiety/distress, to help understand their individuals needs better, tailor their support provision and improve their health and wellbeing.
- Wirral Council and Wirral Clinical Commissioning Group are looking at ways to reduce high cost care placements for people with complex needs and reduce the cost of hospital admissions; there is also an appetite to continue to develop our digital strategies by piloting new technological interventions and innovations.
- Wirral wants to advance in our approach to the utilisation of technology across all sectors. We are developing our digital strategy across the Council. Telecare and telehealth has been utilised for a long time and we are keen to explore the benefits of Biometric Technology.
- The project will help develop service provider arrangements that involve enabling and empowering Service Users and their families through technology.
- The problem to solve has remained the same for the implementation stage of the project.

Project Objectives detailed in the discovery phase application:	Progress towards overall objectives
➤ Enhance the role that information and digital technology plays in commissioning and delivery of health and social care services across Wirral and help people develop their own solutions and address challenging behaviour.	✓
➤ Work with multiagency partners collaboratively on a new model of care by exploring the benefits of computational systems that can recognise and respond to a service user’s emotions, transforming the delivery of social care.	✓
➤ Explore a partnership of biometric technology and health and social care professionals, to develop a model that can pre-empt care needs ahead of time, to enable positive intervention.	✓
➤ Developing data visualization tools and machine learning algorithms to automatically retrieve instances of challenging behaviours in sensor-based data, to help identify environmental “triggers” and appropriate care staff interventions.	✓
➤ Explore how information and technology can bring improvements in efficiency, effectiveness and help to improve the overall quality of care for residents.	✓

Research Methodology [5%]

The Project utilised £20,000 funding, from 2nd July 2018 to 31st October 2018 to establish the discovery phase.

Key Partners to support the Discovery Phase:

1. Autism Together
2. Wirral Metropolitan Borough Council
3. Wirral Clinical Commissioning Group
4. Cheshire and Wirral Partnership NHS Foundation Trust
5. Northeastern University Boston

Collaborating with a Research Partner:

- Work was conducted very early on to establish academic partners to strengthen the approach to the research methodology.
- The Wirral Project has identified Professor Matthew Goodwin from Northeastern University Boston, Massachusetts to provide the academic insight, knowledge and support with Bio-metric Assessment of Autism Sensory Processing (BAASP) Project.
- Professor Goodwin has visited the Wirral to support the project whilst in the discovery phase.
- Professor Goodwin met with the families’ in Wirral who have expressed an initial interest to be involved in the pilot.

Literature Review:

- Cheshire and Wirral Partnership Trust Library Team conducted a full literature review on “Biometrics in the care of complex autism” which generated 50 academic articles.
- The leading academic most relevant to the Project is Matthew Goodwin, who is from the United States and is supporting the Wirral Project.
- The literature review conducted an assessment of the current state of research on this topic to familiarise the project team with the methodology, content and conclusions of others' research and to articulate the key research issues, to ensure there is an understanding of the broad context.
- The project team found it helpful to understand methodologies used in past studies of similar topics.

Partnership with Service Users and Families:

- Families support the idea that there is a need for better understanding of people with autism who are non-verbal are feeling prior to them presenting risk behaviours;
- Autism Together have held meetings with the families of the Service Users who have been identified as being candidates to participate in this project.
- Families of Service Users were fully consulted with, to identify whether they agreed that there was a need to be engaged with the project.
- Autism Together organised an information workshop with the families. Professor Matthew Goodwin attended the session to help answer questions from the families.
- Fifteen families attended the session to discuss the project/initiative. Seven families have agreed to be involved in the initiative and are suitable for the pilot using the technology.
- Regular discussion with Service User’s has taken place at the Service Users/ family Forum which was arranged for the project. The regular dialogue enables the families to be at the heart of the project.
- Families feel that the project is positive and are supportive. Due to mental capacity issues of the cohort, the Project Team will ensure that best interest meetings are undertaken.
- Autism Together have developed an easy read service user guide.
- The Project has full consideration for research ethics. The project members are working closely with families to ensure that consent is in place for those individuals and families who are involved in the initiative.

Staff Engagement:

- Team meetings were held with the staff in scope of supporting Service Users and their families involved in the project.
- There were a few consultation sessions with staff teams to establish the workability of project in a residential setting.
- Staff were very enthusiastic about the project benefits and will be a valued part of the project team for the implementation phase.

Ethics Consideration:

- There are service user guides in an easy read format to show Service Users the details of the project.
- The project team considered the projects ethics in which the philosophy and approach to dealing with values relating to human conduct and engagement was at the forefront of the project.
- Ethics is relevant and very important in this research project, considering the intervention and support arrangements for the families involved.

- The project involves information sharing of Service Users' personal health data, and therefore the project is actively engaging with families, care professionals, software and hardware developers about how the information will be shared.
- The ethics approach was submitted to Autism Together Access Review Group which is the lead/project delivery organisation's Independent internal ethics committee.

Identification of Equipment:

- Product and costs analysis was conducted on a range of hardware equipment/technology solutions for the project to determine which would be the most suitable item of biometric technology.
- A range of hardware was purchased and piloted to identify several products to meet the individual needs of those Service Users taking part in the research project.

Identification of Consultants and Supplier organisations:

- A range of research was conducted by Autism Together to consider which organisations can support the project methodology and objectives through their organisations services, products and equipment.

Identification of Hardware:

- Hardware is available on the open market to monitor the environment, we have decided upon an Omron Sensor which measures, light, sound, temperature and barometric pressure.

Identification of Coders:

- The project identified Programmers within the discovery phase to support the hardware integration process.

Research findings [14%]

Approach to how objectives will be met	Project Status
The project will be closely monitored through partnership meetings, ensuring that corrective action can be taken where required against project plan.	✓
The Third Sector Service Provider Autism Together will work closely with their Service Users and their families, and project partners to learn from the pilot by collating feedback.	✓
Service User outcomes will be measured, analysed and compared - how many people had reduced out-bursts of anxiety and challenging behaviour.	✓

- This project is exploring technology that can support residents through proactive alert monitoring utilising Biometric Technology.
- Gaining consent and engagement from people who have profound disabilities is challenging but the service provider Autism Together have a long history of including Service Users in decision making, using mental capacity assessments, best interest decisions, and also independent advocates where appropriate.

- Service Users were engaged and trained with the biometric technology in preparation for the delivery of the project.
- The Project Team worked closely with Service Users, families and health and social care professionals to gain a better understanding of the “triggers” for heightened stress and anxiety in a variety of environmental situations, which could enable professional support staff to develop and implement more efficacious strategies to help individuals with learning disabilities and autism to better prepare for and manage their sensory world.
- Biometric technology measures minute physiological changes such as surface skin temperature, heart rate and sweating. The project explored how biometric technology can be worn by people with autism who may be non-verbal or unable to communicate how they feel. Real-time readings were taken with a small group of Service Users to help identify periods of high anxiety, enabling them to intervene early to any dramatic behaviour changes.
- Biosensors can continuously and passively monitor cardiovascular, electro dermal, and physical activity to assess an individual’s physiological levels in an unobtrusive and untethered way. The Project will cross-reference data with additional information from an individual’s environment (date, time, number of people present, light, sound, temperature), to accurately assess which specific stimuli correspond with observed increases/decreases in stress and anxiety.
- During the discovery phase, a pilot was conducted with one individual in which information on anxiety levels were cross-referenced with detailed staff notes on the dates, times and locations of behaviour changes and extreme incidents. Staff noted levels of heat, noise and light in each situation – such as loud TVs, bright sunlight or hot radiators – and merging this data with biometric readings to understand how people are reacting to sensory stimuli.
- Data collected was cross-referenced with staff observations, recording when and where each anxious episode occurred, taking account of light, heat, noise and proximity to others. The data was analysed, creating a unique insight into behaviour patterns, taking account of sensory stimuli that may have an influence on behaviour.
- This is the first time that biometrics is being piloted in the United Kingdom with this client group, to reveal how people on the spectrum react to everyday environmental stimuli.

Hardware:

- So far, the Project Team have identified what bio-metric devices would be most suitable and whether there is an opportunity to manufacture devices specific to this project. Work is ongoing with the Empatica E4 wristband and these have the required specification to capture the Electro-dermalogical Data that is required to indicate anxiety levels.
- The Project Team have identified issues with the strap of the E4 which makes the device difficult to fit to a third party. Discussions are ongoing with a manufacturer of fitness wristbands who may be able to produce a comparable device at a lesser cost.
- The Project Team have identified a system for video capture, but advice is that we consider a time capsule/hard drive back up on top of cloud based secure storage for data.
- The Project will use a laptop as a driver for the system and this will serve to Unix time stamp the data as it is being captured from the sensors.

Software:

- Identification of Analytic software was conducted in the discovery phase.
- Similar work has been done in the United States and Autism Together have identified some collaborators who are able to establish a workable bridge between the devices. One of the primary issues is that each sensor drops its data in a different platform and therefore the Project Team need to develop a user interface that is intuitive and able to provide visual representation of the data and its sub-sets.
- The Project Team are looking at the legal implications of working across the international borders and Autism Together have commissioned a Barrister to draft contracts.

Analytics:

- The Wirral Project concept originated from work undertaken by Prof Matthew Goodwin at North Eastern University. Autism Together have negotiated with Matthew and secured his services as academic advisor on the project. Matthew has suggested another United States collaborator who may be able to develop the back-system algorithms to provide some initial data analytics.
- Autism Together have also commissioned an architect to draft drawings of the service environment so that the project team can establish the best positions to deploy the technology.

Validating initial ideas [14%]

The project supports the objectives within the National Think Autism Strategy, Domain 3: Health, Care and Wellbeing:

- Widespread use of tailored communication methods and recognition of sensory, communication and environmental needs
- Preventative support in line with Care Act 2014

The project aims to support commissioners and service providers in the future to predict in advance what interventions will have the greatest impact to supporting individuals to live comfortably at home – leading to early intervention and preventative approaches to care for residents across Wirral.

In the discovery phase, adults with more severe forms of ASD were observed repeatedly in their home setting with the Biometric technology, and were able to capture Electro Dermal Activity (EDA), skin surface temperature, and three-dimensional motion wirelessly in a wrist-worn form factor.

Reliable and valid peripheral measures of physiological arousal and emotion regulation from individuals with ASD in an untethered way in natural environments over time enables an easy and efficient way to gather biomarker data that could be used in diagnostic, phenotypic, and clinical/intervention explorations in autism and related neurodevelopmental disorders.

- The project is ethically sound with the support of key partners sharing expertise and insight to guide the project through its various stages.
- Hardware is available to monitor stress levels, using an Electro Dermal Activity sensor which is integrated in a Bio-metric device called an E4.
- Coding can be developed further to ensure that the hardware works together.
- Front Line Staff feel that a system to monitor the environment would be useful and possible.
- The Project Team can foresee the benefits of the project implementation stage, which will enable the pilot to be fully managed over the next five months from November 2018 to March 2019.

Learning from discovery phase process [5%]

- By nature of their Autism and learning disability, the people who we think this technology will help in the first instance will struggle to understand the concept of the project. To ensure that we have considered their needs fully we have conducted Mental Capacity Best Interest meetings with other stakeholders, including social work community health and advocacy colleagues. Families have also been involved in these Best Interest Meetings. We have developed an easy read guide; however this is still not a format that is easily understandable for the individuals this project is designed to assist.
- Data Protection and Information Governance issues have had to be carefully managed; we have used a system of identifier codes so that individuals are not able to be identified through the data by anyone else other than the local team. We have worked to ensure that data is secured locally on a server.
- The amount of data that we will be collecting will be significant. In order to direct the data analyst to behaviour of interest for this project, we need to find a way of marking the incident in the data timeline. We have identified an 'aha' button which can work alongside the other hardware that staff can press, to ensure a flag is in the data.
- Individuals who are not used to wearing a watch style device find the sensation unusual. The Project Team have had to therefore develop some strategies to support people to get used to wearing the biometric wristband; these have included buying "imitation" wristbands, decorating the wristbands with different appealing colours, and staff modelling the bands so that people become familiar with seeing them in their environment.
- Support Staff meetings indicated that some staff were unsure how to use the technology and what the requirements would be on the staff to implement and monitor. Whilst we worked to communicate with families and the Service Users from the outset, we didn't fully consider the impact on the staff teams, so we have revisited our communication approach with them. They are now all fully briefed on the project and keen to get involved, and we will be providing training as part of the implementation phase.
- Families have been excited about the potential benefits of the project, they have been very supportive, but we have had to manage their level of expectation.

