



To further research development for rare muscular diseases, Yumen Bionics and Ann.I.D. are developing sensory technology that measures muscle activity and position of the arm. Currently, most research for these diseases is done by monitoring the legs, making the research dependent on the functioning of the legs - a function that diminishes in earlier stages of the disease than arm movement - this technology aims to enlarge the target group and data diversity. Their technology also opens up the possibility for distant monitoring, creating the opportunity to get more representative data on daily muscle activity and fatigue.

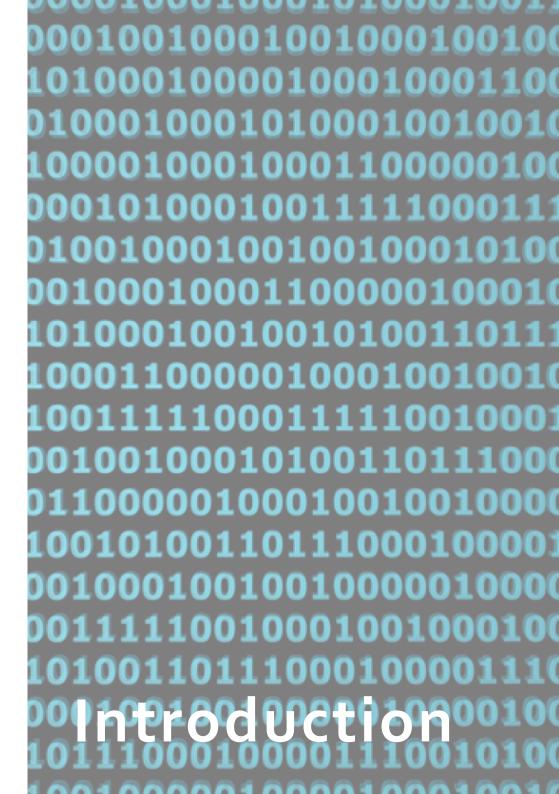
The respondents that partake in this research are at different stages in these diseases. Some of these respondents participate in forms of research 86 times in three years, which currently consists of a blood test, a respiratory test and a meeting with a physician, taking up a full day. By decentralising this procedure, the bar of entry for these forms of research will be lowered. Participating in research is a way for respondents to help future patients, get early access to medicine, and get in touch with other patients.

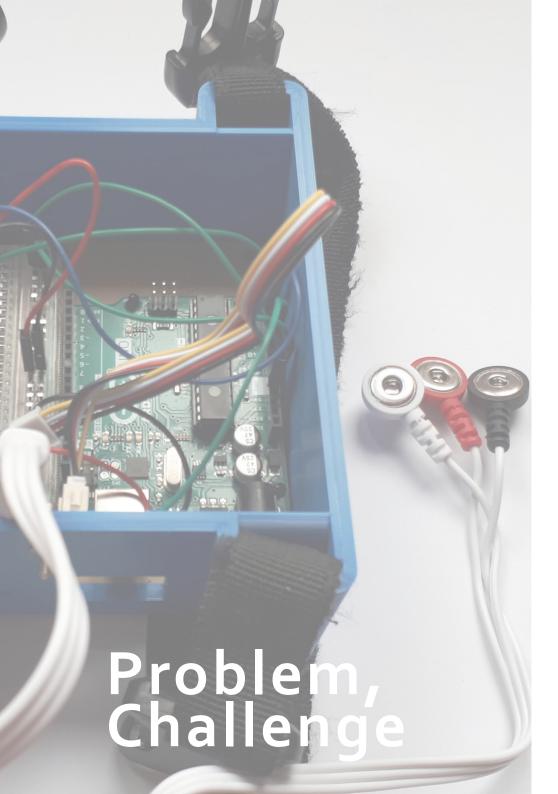
The researchers aim to test the effects of medicine that is in development, and see this new technology opening up possibilities for getting more valuable data on the daily lives of their patients. They want something to give back to the patients for participating in the research and something that keeps the respondents participating.

This design project is also done with the support of Samenwerkende Spierfondsen, a collective of funds that aim to raise awareness and further research for these rare muscular diseases.

The aim of the project is to design a smart object that is informed by the data generated by the respondent. This product should reward the user for partaking in research and provide a positive moment on a bad day.

This project was done with an emphasis on prototyping and user testing during a 15 week semester at The Hague University of Applied Sciences.





Problem definition

Patients of SMA type II and III that participate in research are at a bigger risk of dropping out from the program if they are not sufficiently rewarded, which would decrease the research data generated for medical advancement.

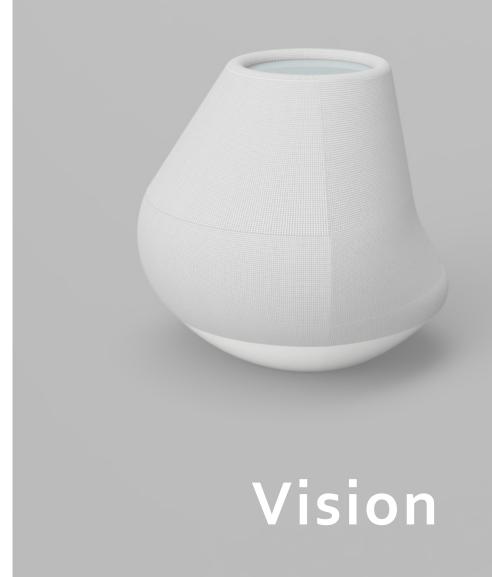
Design challenge

Research participants suffering from type 2 & 3 SMA between the ages of 18-35 need to be rewarded for their participation with a smart object that is informed by research data.

Design Vision

We aim to design a smart object that will provide the patients with a greater sense of reward for participating in research, and take away from the impact of a negative day while being consistently engaging over a longer period of time.

Interacting with this object should be so intriguing that the user will have a feel confident in displaying the product on their body and immerse them in a product experience that takes away the focus of participating in the research.





For this project, the intention is to develop a smart object interface towards a target group of SMA patients that are 18 - 35 years of age. Due to the differing nature of medical devices and research standards between countries, the target group has been further refined to include only patients that receive care in The Netherlands and countries with congruent health regulations to The Netherlands.

Most adults that have SMA were diagnosed as small children and have grown up coping with the disease. This typically means that, more than other people, they have been and continue to be dependent on parents or caretakers for much they do in their daily lives. Depending on the severity of their condition, daily things like dressing, eating, and other routine activities can be serious challenges. Almost all patients with SMA eventually rely on a wheelchair for advanced mobility. Some patients note this appearance of helplessness often leads to misunderstandings about how to be approached or interacted with, sometimes to the extent of being treated as though they are intellectually disabled (Genentech, 2020c).

Like people without SMA, SMA patients tend to value friendship, inclusivity, and independence. In fact, friendship is a consistent motivation behind why they opt to join clinical research, as it provides the ability to meet others like themselves. Friendships can be catalysts for independence as well, since it can give an opportunity for them to socialize separately from their parents or caretakers. Friends can be one of the few available avenues by which they can have experiences beyond their typical capabilities (Genentech, 2019a). An additional component of independence is the ability to advocate for themselves and take charge of their own well being as often as possible. Technology is an important enabler of independence in that respect, as it allows for communication and mobility and helps patients build an identity for themselves (Genentech, 2020b).

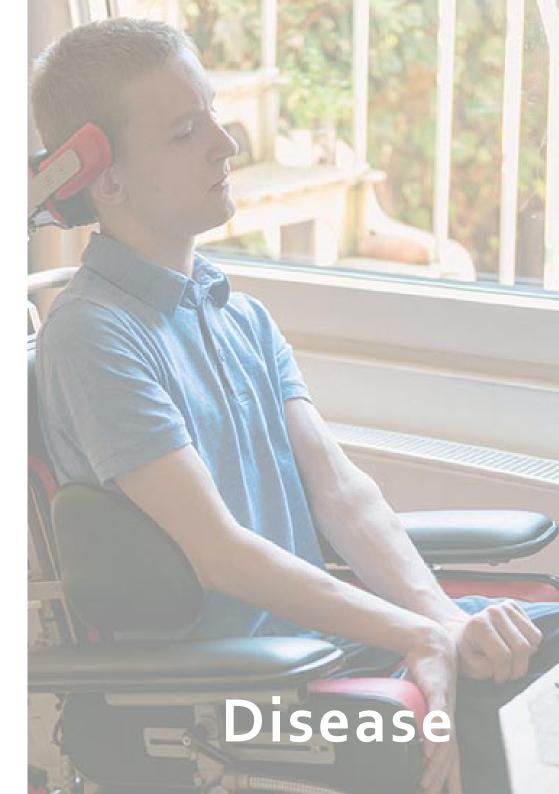




Spinal muscular atrophy (SMA) is a motor neuron disease that affects the central nervous system, peripheral nervous system, and voluntary movement muscles. Symptoms primarily involve weakness of these voluntary muscles. Muscles that are closest to the center of the body are most affected, often including: shoulders, hips, thighs, and upper back. The lower limbs are first to be affected, and to the greatest degree.

Because SMA involves the loss of motor neuron cells located in the spinal cord, the true issue of the disease is that the signals sent by the brain to rouse the muscles can never reach the intended muscle. This is directly due to the discontinuity in the signal path. The muscle atrophy occurs as a by-product of not being stimulated and used regularly (Muscular Dystrophy Association, n.d.).

The most widely diagnosed form of SMA is known to have a wide fluctuation in the age of onset, symptoms, and rate of progression between patients. This variability necessitates a classification system of type 1 through type 4 (Muscular Dystrophy Association, n.d.). Each type relates to the age of onset, and since the age of onset roughly correlates with the degree to which motor functions are affected, the severity of expected symptoms. Patients of type 1, children who display symptoms at birth or in infancy, can be expected to have the lowest level of functioning. Type 2, type 3, and type 4 are increasingly later onset groups and generally display respective increases in levels of motor function.





When collecting the data about patients with neuromuscular diseases, the data collection from arm muscles with the use of EMG and motor sensors is preferred, as the upper limbs tend to be affected at later stages of the disease than the lower limbs. This gives the researchers a longer period of opportunity for data collection.

Before placing the EMG sensor, it is worth considering the movements that the patient will perform with his upper limbs and more specifically, the elbow flexors. Although the construction of the arm is not highly complex, its anatomy dictates that some of the muscles of the same function will take more load than the others depending on the position and or the rotation of the arm. An example of that would be the elbow flexors: such as the biceps brachii long and short heads, as well as the brachialis. The brachialis will be more activated when the wrist is oriented in the neutral position (i.e. with the palm facing inward). While the biceps brachii will take most of the load in the supinated (i.e. with the palm facing downward) grip.

It is also interesting to note that depending on whether the arm is pointing inwards, or towards the toros, the long head of the biceps brachii will be stimulated more. Thus the opposite is true when the arm is aimed outwards and the short head takes the majority of the load.

When we look at the construction of the triceps brachii it is made of 3 heads: the long head, the lateral head, and the medial head. The activation between the 3 different heads cannot be changed by angling the wrist like the biceps brachii. However, the relationship between the position of the arm and the torso will change the EMG activation. As an example, the triceps brachii long head will be more stimulated when the arm is placed overhead.





Collection of research data from SMA patients is usually accomplished with the use of an electromyography (EMG) sensor and/or three way motion sensor. The EMG sensor will measure the difference in electrical pulse in the muscle, and output a voltage from 1.5 to 3.5 volts (Electromyography for Spinal Muscular Atrophy, n.d.). This is normally monitored on an oscilloscope. The three way motion sensor is able to detect motion of the arm to which it is attached and gives an x, y and z positions as output by using a gyroscope (Kiwi Electronics, n.d.).