



Queensland  
University  
of Technology

**PHYSICAL RECOVERY AND  
REHABILITATION FROM A  
BRAIN INJURY**

**MENINGOCOCCAL, MENINGITIS & SEPTICAEMIA**

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**PHYSICAL RECOVERY AND REHABILITATION FROM A BRAIN INJURY -  
MENINGOCOCCAL, MENINGITIS & SEPTICAEMIA**  
ABSTRACT

**ABSTRACT:**

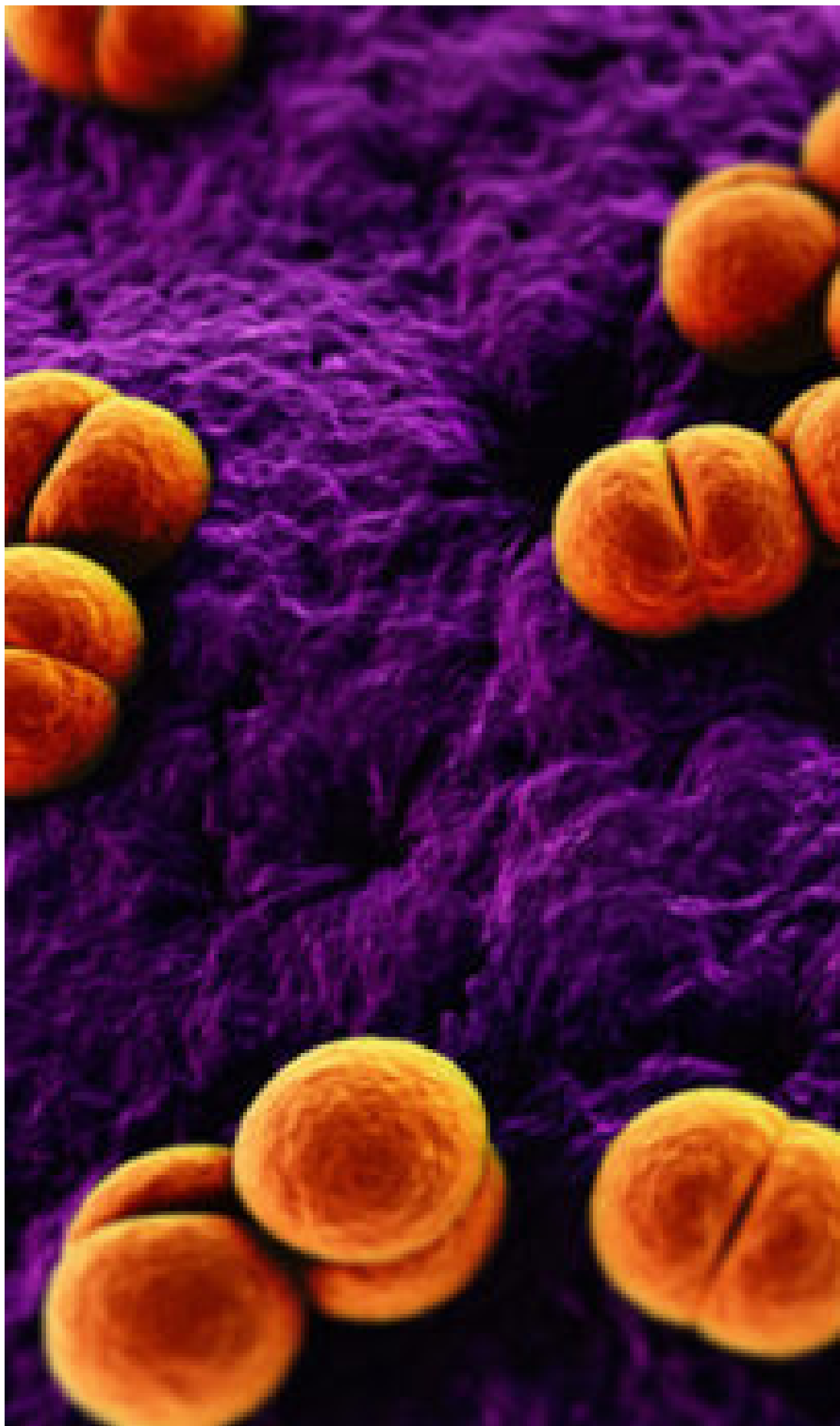
The following dissertation is to develop recognition of Acquired Brain Injuries and the importance of subsequent physical recovery and rehabilitation of adults aged 18 to 25 years, that result from Meningococcal, Meningitis and Septicaemia.

Physical movement is crucial for the physical recovery and rehabilitation of a patient. However, the state in which a patient begins their physical recovery and rehabilitation journey is difficult to achieve by themselves. Meaning that help is required from a nurse, custodian or family members to achieve and develop strength. There is very limited information available for the physical recovery and rehabilitation stages of recovery of physical movement.

There is a difference between recovery and rehabilitation as a process for patients. Recovery is defined as the regaining or the possibility of regaining something that is lost or taken away (Dictionary.com, 2020). For the purpose of this dissertation it is the restoration or the return from sickness while admitted as an inpatient, this is, while a patient is in hospital. Rehabilitation is to restore to a condition of good health, ability to work or the like, meaning the patient's journey as an outpatient, after returning home but still requiring medical treatment (Dictionary.com, 2020).

The research obtained in the literature review aims to explore what effects Meningococcal, Meningitis and Septicaemia has on a patient's physical recovery and rehabilitation and what tools or experts are available to assist.

# 01 INTRODUCTION





The focus of this dissertation is to develop recognition of acquired brain injuries and the importance of subsequent physical recovery and rehabilitation of adults aged 18 to 25 years, resulting from Meningococcal, Meningitis and Septicaemia.

On average the human brain takes 20 years to fully develop therefore, should adults aged 18 to 25 years develop an Acquired Brain Injury, they have a more difficult time healing and rebounding than young children or adolescents (Meningitis Research Foundation, 2020). Special care and attention are required to achieve physical recovery and rehabilitation.

Meningococcal, Meningitis and Septicaemia are individual diseases, that often present together, are severe, deadly and affect the brain with swelling. Resulting in an “overwhelming and life threatening immune response that can lead to tissue damage, amputation, organ failure and death” (Centres For Disease Control and Prevention, N/a). However, the severity will result in the patient requiring physical recovery and rehabilitation to regain physical movement. Physical recovery and rehabilitation are the process where patients learn to regain physical movement through mobility exercises and motor skills training. Physical movement can start with the patient simply learning how to roll over in bed or how to transition from sitting to standing. This will progress to tasks of more independence such as personal hygiene care, eating and drinking.

The aim of this project is to improve patient’s physical recovery and rehabilitation from an acquired brain injury as a result of Meningococcal, Meningitis and Septicaemia, focusing on the importance of physical movement and at home/ independent methods.

For example, the physical recovery and rehabilitation needed for a patient once they have healed sufficiently to commence physical movement after tissue damage, amputation or organ failure require detailed and attentive plans. Physical movement starts with small gestures then leads into relearning basic human and daily function. The patient’s mobility and motor skills will be challenged significantly during this process even if the patient isn’t coming to terms with any tissue damage or amputation.

The below Figure 1.1, provides a schematic outline of this dissertation.



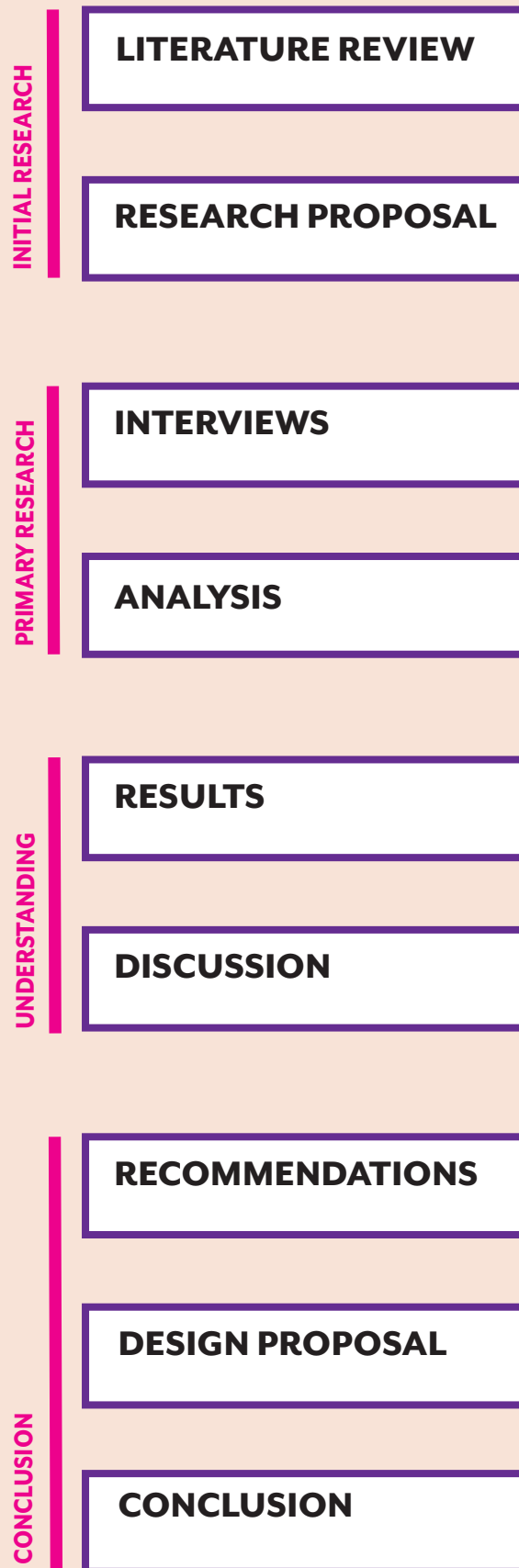
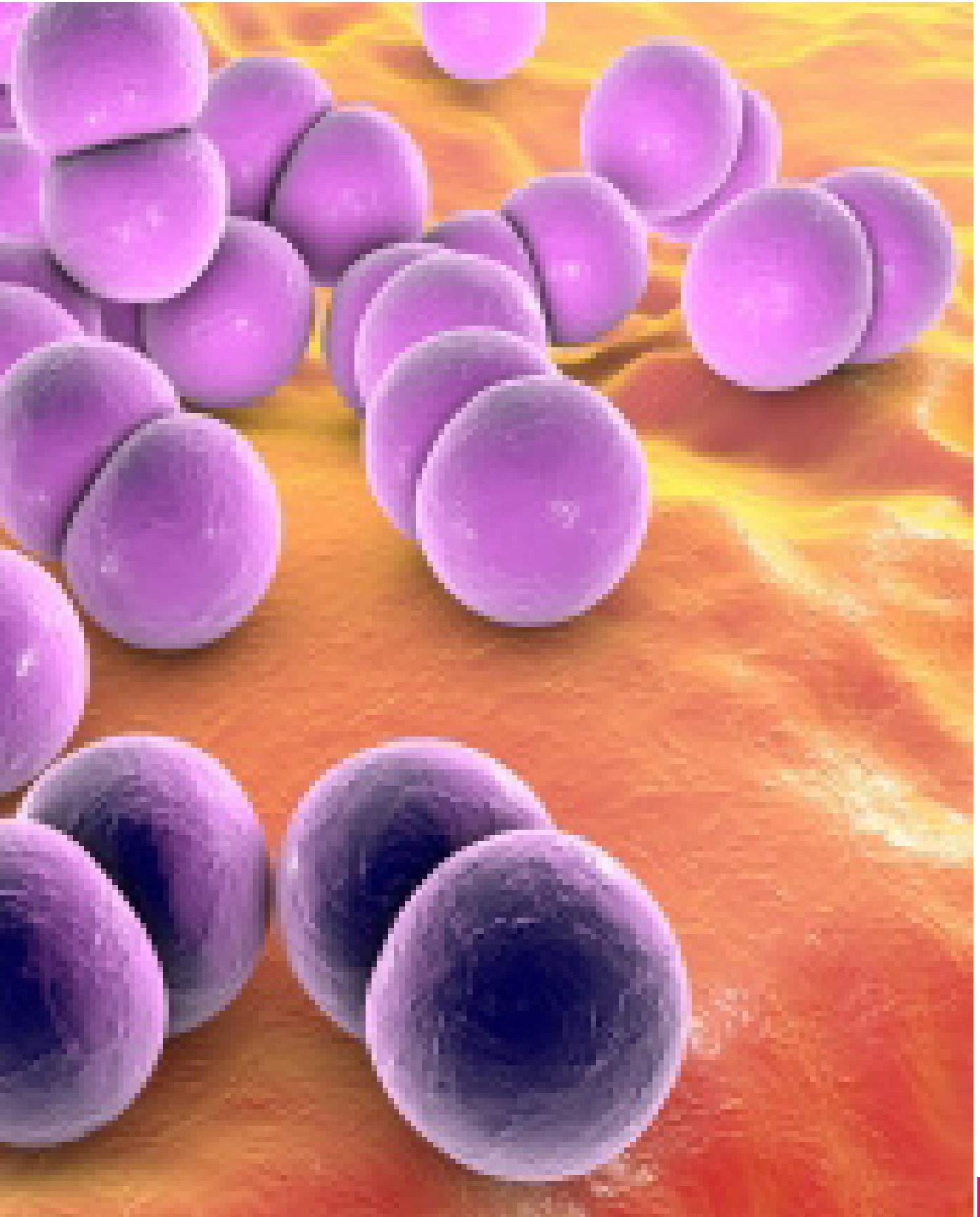


Figure 1.1 REPORT STRUCTURE

# 02 LITERATURE REVIEW





Brain injuries are common through various incidents for all ages. Brain Injury Australia's medical term for brain injury may be referred to as an acquired brain injury, or "ABI". Brain Injury Australia have estimated that there is over 338,700 Australians affected by an ABI. Of these individuals they are either recovering or living with restrictions to their daily activities. (Brain Injury Australia, n.d.).

Injuries to the brain can occur through various scenarios and can cause a wide range of outcomes. The Queensland Department of Health, have categorised how a brain injury can occur, they are but not limited to (Queensland Government - Queensland Health, 2020):

- Traumatic Brain Injury (TBI),
- Stroke,
- Infection and disease (e.g. Meningococcal, Meningitis and Septicaemia),
- Alcohol and drug abuse.
- Brain tumour,
- Near drowning or other anoxic (without oxygen), ) (Queensland Government - Queensland Health, 2020),

Outcomes from the above can result in:

- Impaired Physical Abilities- weakness, tremor, spasticity
- Medical Difficulties - epilepsy
- Altered Sensory Abilities - impaired vision, touch, smell
- Impaired Ability to Think or Learn - memory problems, attention problems
- Altered Behavior and Personality - short tempered, lethargic, depressed
- Impaired Ability to Communicate - slow or slurred speech, difficulty following conversation ) (Queensland Government - Queensland Health, 2020),

Although there is a large range of information from recognised sources concerning ABI's and how a patient can be affected, there is limited information on understanding the recovery and rehabilitation in terms of their physical movements. One of the severe ABI contributors are people who contract Meningococcal. Meningococcal is a fast, aggressive illness often associated with Meningitis and Septicaemia.

There is a difference between recovery and rehabilitation as a process for patients. Recovery is defined as the regaining or the possibility of regaining something that is lost or taken away (Dictionary.com, 2020). For the purpose of this dissertation it is the restoration or the return from sickness while admitted as an inpatient, this is, while a patient is in hospital. Rehabilitation is to restore to a condition of good health, ability to work or the like (Dictionary.com, 2020), meaning the patients journey as an outpatient, after returning home but still requiring medical treatment.

The recovery of a patient having shown physical progress to be discharged, meaning having some control over basic functions such as sitting to standing movement, personal hygiene care (brushing teeth and hair, showering, using the toilet) and eating. The patient's recovery process starts with movements they can achieve whilst still laying down, such as rolling over in bed, and progress to being able to walk short distances, for example from bed to an ensuite bathroom.

Rehabilitation is defined as the continuation of the healing stage recovery to gain further stamina and independence such as learning to do household tasks. The patient's rehabilitation process continues from what they have achieved in the recovery stage. The patient depending on the severity of their injuries, will progress from the recovery stage to being able to walk longer distances, stand for longer periods of time (standing instead of sitting to shower), to being able to operate a vehicle.

## MENINGOCOCCAL:

Meningococcal refers to any illness triggered by bacteria called *Neisseria Meningitidis* or *Meningococcus* (Centers for Disease Control and Prevention, 2020). Recognised as the cause of the worldwide spread of Meningitis and Meningococcal, *Neisseria Meningitidis* is responsible for significant morbidity and mortality in children and adults through meningitis and septicaemia (Stephens D. S., 2007) (Stephens N. G., *Neisseria meningitidis: Biology, Microbiology, and Epidemiology*, 2015). *Neisseria Meningitidis* is also the cause of epidemic cerebrospinal fever, infectious disease that's characterised by the inflammation of the meninges, bacterial meningitis, septicaemia, pneumonia and less common septic arthritis (Vocabulary.com, n.d.) (Pollard, 2018).

Meningococcal also includes infections in the lining of the brain and spinal cord (meningitis) and bloodstream infections (Septicaemia) (Centres for Disease Control and Preevention, 2020). Meningococcal virus is spread via people through the exchange of respiratory and throat secretions (saliva) (Centers for Disease Control and Prevention, 2020).

The six strains, serogroups, of Meningococcal, A, B, C, W-135, Y and X, have one or more antigens (irritant) in common. These are based on different polysaccharide structures that comprise of large molecules made of smaller simple sugars such as glucose (Dictionary, 2020) (Merriam-Webster, Incorporated, 2020) (Stephens D. S., 2007). While the serogroups are known, medical professionals believed that there was only a single strain responsible for Meningococcal prior to an outbreak in the 1990's where a second serogroup was discovered in Sub-Saharan Africa.

Serogroup A Meningococcal causes outbreaks that are highly clonal complexes which when emerge spread rapidly, historically resulted in the major cause of the diseases in Sub-Saharan Africa (Caugant, 2009) (Centers for Disease Control and Prevention, 2015) The major cause of sporadic or endemic disease is Serogroup B, which leads to prolonged outbreaks that cause mobility and mortality in Europe, Cuba, US Pacific Northwest and New Zealand (Stephens D. S., 2007). The rates of the disease are the highest in young children and increase again in adolescents and young adults this relates to increase transmission and acquisition (Stephens D. S., 2007)., Figure 2.1, shows where each serogroup is most prominent.

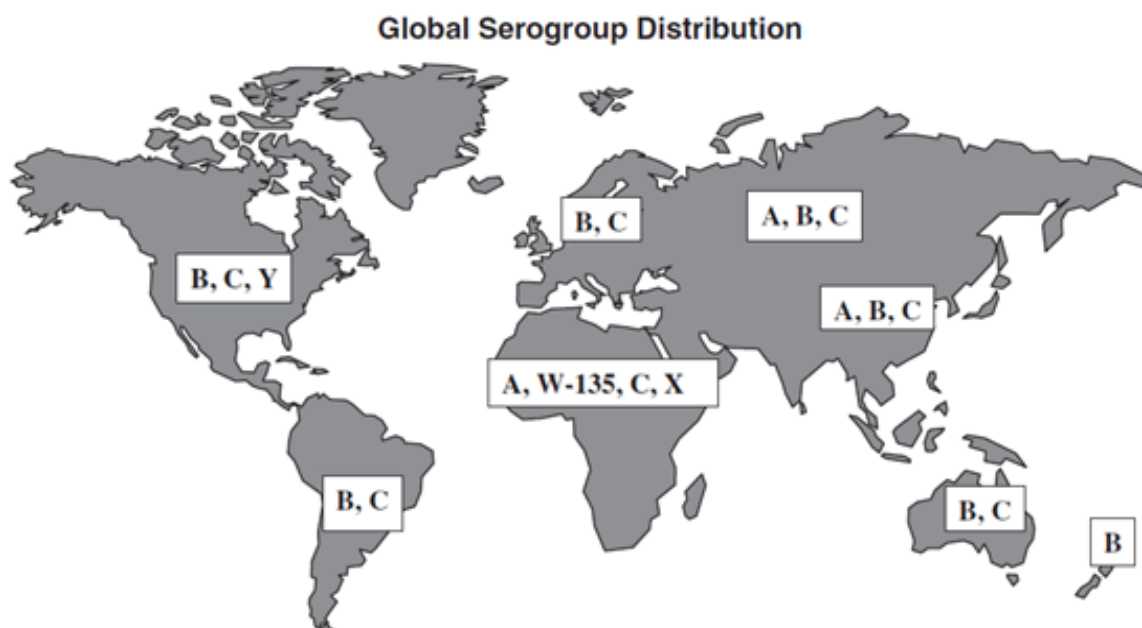
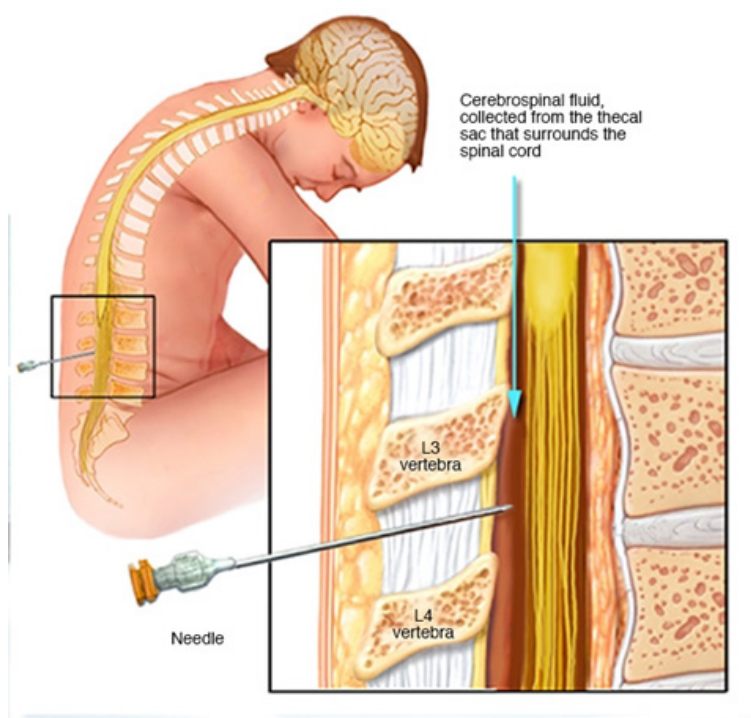


FIGURE 2.1 GLOBAL SEROGROUP DISTRIBUTION (Stephens, 2007).

### MENINGITIS:

meningitis is the infection of the “lining around the brain and spinal cord (meninges) which can cause dangerous swelling of the meninges lining surrounding the brain” (Meningitis Research Foundation, 2019). With this “inflammation of the protective membranes covering the brain and spinal cord”, a definitive diagnosis is achieved via Lumbar Puncture (Spinal Tap) (Mayo Foundation for Medical Education and Research, 2020). A lumbar puncture, Figure 3, is a procedure which is performed in a patient’s lower back (lumbar region) which entails a “needle being inserted between two lumbar vertebrae to remove a sample of cerebrospinal fluid” (Mayo Foundation for Medical Education and Research, 2020).

Meningitis restricts physical movement of the patient, by the swelling of the central nervous system, brain, spinal cord and nerves, interfere with their senses (Krucik, 2014). This can result in hearing issues, light sensitivities and vision problems which lead to poor coordination, dizziness and clumsiness. For the patient to reduce these effects they will require physical recovery to gain back basic mobility skills (Krucik, 2014).



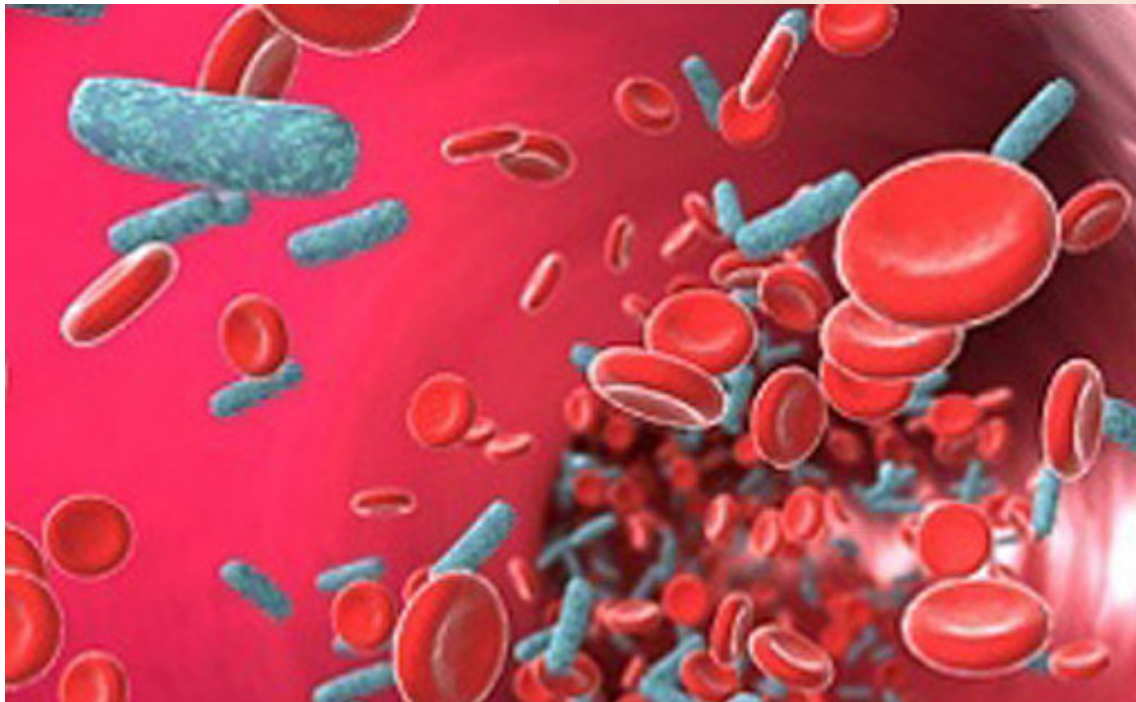
© MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH. ALL RIGHTS RESERVED.  
**FIGURE 2.2 LUMBAR PUNCTURE LOCATION**  
(Mayo Foundation for Medical Education and Research-, 2020)

### **SEPTICAEMIA AND SEPSIS:**

Septicaemia is the introduction of bacteria in the bloodstream that causes blood poisoning which triggers Sepsis (Meningitis Research Foundation, 2019) Figure 2.3.

“Sepsis is the overwhelming and life-threatening response to infection that can lead to tissue damage, amputation, organ failure and death” (Meningitis Research Foundation, 2019). Sepsis occurs when the infection a patient already has (in their skin, lungs, etc.) causes a chain reaction throughout the whole body, without treatment can lead to varying degrees of tissue damage, amputation, organ failure and death (Centers for Disease Control and Prevention, 2019).

Physical recovery and rehabilitation are needed once the patient has healed of a stage to start physical movement. Detailed recovery and rehabilitation plans will provide patients with personalised attention when relearning basic and daily function, mobility and motor skills, when accommodating to, if any, tissue damage, amputation or organ failures.



**FIGURE 2.3 SEPTICAEMIA IN THE BLOODSTREAM (Prynne, 2014).**

### **SYMPTOMS:**

Meningococcal range and severity of symptoms haven't changed or evolved since Meningococcal Meningitis was first described in 1800's. However, Meningitis can be difficult to identify in the early stages but will develop rapidly in hours. Meningitis symptoms can be mistaken to those of a common cold, which consist of drowsiness or difficulty to wake, loss of appetite and nausea or vomiting (Meningitis Centre Australia, n.d.). As the symptoms of Septicaemia present themselves very quickly, the appearance of the patient can look extremely sick. (Seladi-Schulman, 2018).

There is a wide range and severity of symptoms for Meningococcal, Meningitis and Septicaemia, the most common physical symptoms are as follows (Australian Government, Department of Health, 2019) (Meningitis Centre Australia, n.d.) (Seladi-Schulman, 2018);

- Inadequate blood flow
- Muscle aches, neck, leg or joint pain, difficulty walking
- Fever or temperature, Chills, Cold hands and feet
- Rapid breathing and heartrate
- Pale or blotchy skin, rash of red or purple spots that don't fade with pressure (Seladi-Schulman, 2018)

### **SYMPTOM EFFECTS:**

These symptoms affect the way the patient physically moves. Before admission into hospital the virus exhibits symptoms that reduce the patient's ability to move, the most common is neck stiffness. This could also be accompanied with aching muscles, joint irritability and difficulty walking all together, an example of this is the timeline of events and symptoms in Appendix A – Patient Experience.

Another example of how fast symptoms can progress has been included in Appendix B - Caleb Thorburn aged 2. Caleb passed away as a result from Meningococcal Group B within 17 hours. Caleb's journey with this disease started on Friday 5th April with normal family activities with his family followed by an unusual early afternoon sleep. Without warning Caleb's health deteriorated rapidly and medical attention was sought, resulting in a misdiagnosis of a viral infection. Caleb continued with no improvement with his fever, until he was unable to support his weight, vomiting and not engaging with stimulation. Caleb was also motionless, twitching. With the onset of purple spots on his arm, neck and torso he was rushed to hospital and placed in intensive care early evening. Caleb's life was fragile and early the following morning was placed into a coma to stabilise his condition and try to relieve some of his pain. Caleb passed away on Saturday 6th April at 9:05am from multiple organ failure from Meningococcal Group B (Meningococcal Australia, Various).

Troy Pocock aged 22 is another example of how fast and serious symptoms can progress, Refer Appendix C Troy Pocock age 22. Troy contracted Meningococcal while on a working holiday in London. Troy began feeling unwell with flu like symptoms on the morning of 29th December. These symptoms progressed to vomiting, diarrhoea, high temperature, joint stiffness and the appearance of a rash on his eyelids, at which time his girlfriend realised the situation had become very serious. She rushed Troy to hospital while he began to vomit blood and his condition was critical. By this stage all the hospital staff could do was place Troy on life support and administer antibiotics. Troy passed away within hours (Meningococcal Australia, Various).



Once admitted the patient might have succumbed to a coma resulting in no control of their physical movement. This must be taken over by a nurse or physiotherapist to prevent long-term muscle damage, there isn't any information available to explain why this is significant. It is also important to move the patient periodically to reduce the outcome of developing bedsores and prevent long-term muscle damage (Watson, 2020).

After the patient recovers from their coma physical movement is very difficult to achieve by themselves. The patient requires help from a nurse, custodian or family member to achieve basic physical movement until they develop strength in their muscles again. There is very limited information available for this stage of recovery of physical movement (Watson, 2020).

### BEDSORES:

Since it is very important to continue to move the patient to reduce the outcome of developing bedsores if one were to develop, the sore would need to be treated quickly to reduce serious infections (Johns Hopkins Medicine, 2020).

Bedsore or pressure sores are ulcers that can develop in areas of the skin that are under pressure from being bedridden.

The sores develop when the skin is deprived of blood supply for more than two to three hours. The sores first develop as red painful areas that will eventually turn purple, left untreated the sores break open and the area can risk infection. If left untreated the bedsores can become deep and extend into muscle and bone (Johns Hopkins Medicine, 2020).

Complications can arise if bedsores or pressure sores burrow to reach bone or joint, they are susceptible to bone and joint infections. Joint infection, septic arthritis, can lead to cartilage and tissue damage while the bone infection, osteomyelitis, can reduce the function (Mayo Clinic, 2020). This will result to significant physical recovery and rehabilitation.

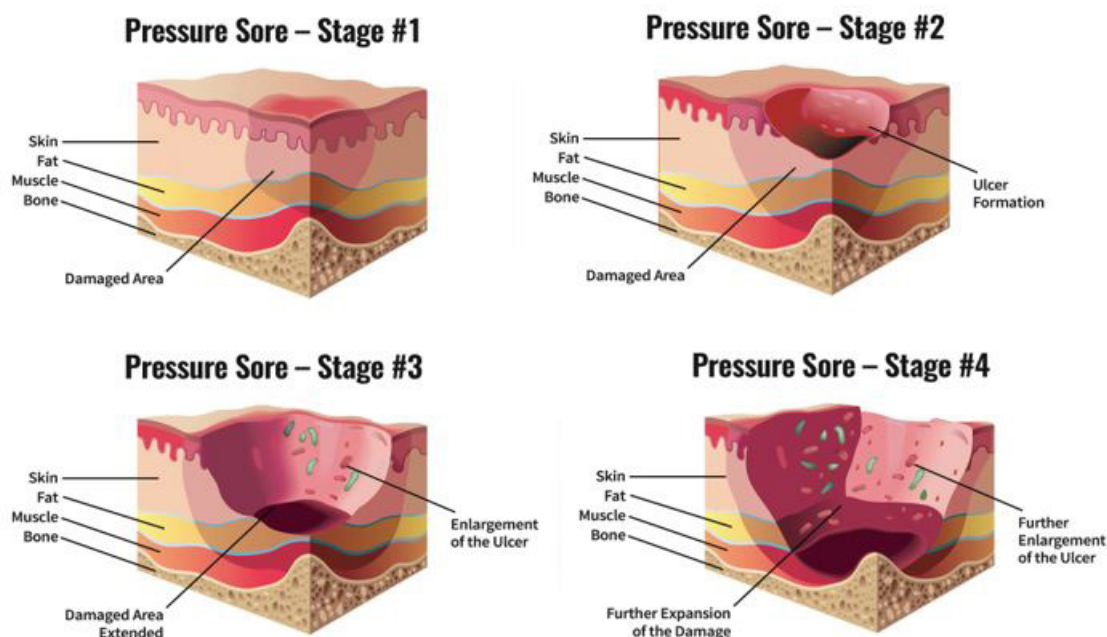


FIGURE 2.4 DEVELOPMENT OF BEDSORES (SCI-INFO-PAGES, 2020)

## PHYSICAL RECOVERY AND REHABILITATION:

Australia's population has been estimated by the Australian Bureau of Statistics (ABI) to be 25.5 million (Australian Bureau of Statistics, 2020). In 1998 an ABS study estimated of these 19 million people 19% (3.6 million) have a disability. Of these 19% the 1999 Australian Institute of Health and Welfare (AIHW) estimated the amount of people who have a disability related to Acquired Brain Injury is 1.9% (338,700). Of these 1.9% of people, 160,200 were severely impacted and require daily support. Another 1.86% (328,000) people have an intellectual disability and 178,000 of this 1.86% require daily assistance (Brain Injury Australia, n.d.).

The Physical Rehabilitation services that are available to patients consist of those which are utilised to help meningococcal patients. Researchers have found that patients who participated in more focused rehabilitation sessions performed better than most of those who didn't. Rehabilitation consists of Mobility Training and Motor Skill Exercises (Mayo Clinic, 2020). These rehabilitation services can take place in outpatient units and are often run as a branch from a hospital where the patient can spend up to a few hours a day, a couple of times a week (Mayo Clinic, 2020).

The Geriatric Adult Rehabilitation and Stroke Service or 'GARSS' is an outpatient services that offers one on one or group patient rehabilitation sessions. Since the outcomes vary patient to patient treatment plans differ to cater to their specific needs. Some of these services include Physiotherapy, Occupational Therapy, Speech Pathologist, Psychologist (Dr Nisal Gange, n.d.).

GARRS is a day therapy service which has been shown to improve a patient's ability to undertake activities of daily living and reduce the risk of post discharge deterioration (Dr Nisal Gange, n.d.).

GARRS staff provide a custom recovery plan tailored specifically to the patients challenges and recovery speed (Dr Nisal Gange, n.d.).

A provider of disability services in Western Australia and Tasmania, VisAbility, offer a range of specialists who are able to help with the recovery and rehabilitation of an ABI. These services include Clinical Psychologists, Orthoptist (vision), Occupation Therapist, Speech Pathologist, Physiotherapist, Orientation and Mobility Specialists and Dietitian. These specialists cover the areas of (VisAbility, 2020);

- Education of living with an ABI,
- Management of behavioural effects,
- Coping mechanisms of cognitive effects,
- Executive behaviours such as planning and organising,
- Speech and language communication skills,
- Physical effects such as limb function and mobility skills,
- Independence of daily and household tasks,
- Vision related issues.

For patients who require work on their Motor Skills and Mobility training Occupational Therapists or 'OT' can provide support while they are regaining their independence. OT's provide assistance for a patient while they are adjusting to life again after sustaining an injury or are in a period of major life adjustment which is impacting their health and wellbeing. An OT provide support in daily living activities such as showering, dressing, grooming and eating and multi-step activities such as household management activities and shopping (Cerebral Palsy Alliance, 2018).

An OT also offer support at a more strategic level of skills development in self-care, self-management, home management and reintegration in community, work or school. Also, with the modification of environments of home, work, school or community with adaptation processes, including the application of ergonomic principles (Allied Health Professionals Australia, 2017).

### MOBILITY TRAINING:

For a patient to start their recovery process they need to start with their mobility. As being immobile for a significant amount of time can affects how you sit, move, balance, stand and walk. A physiotherapist will assist in initial recovery stage when the patient is beginning to move, sit, stand and walk after their inability to move while confined to a bed. Depending on the weakness of the patient they might need to relearn how to (Physiolnq, 2019);

- Roll over while in bed
- Transition from sitting to standing
- Transition from a bed to a chair or toilet
- Walk

Physiotherapist will work with the patient in their rehabilitation process. The physiotherapist will set goals and develop a program to meet their individual needs. Prescribed exercises can improve the patient's strength, coordination, balance and fitness, these can be done during daily activities while standing or walking (Physiolnq, 2019).

### MOTOR SKILLS TRAINING:

Motor skills are required by a person to perform precise, specific and often small movements. Patients who are suffering the effects of an ABI can have trouble completing these movements. These movements are essential for some everyday tasks and may require activities to encourage motor skill development. An OT recommends these, some activities include (Stroke Foundation, 2020);

- Pincer Grasp, the movement of grasping by pinching together the thumb and index finger
- Finger Isolation, stimulating a single finger to do tasks such as pushing or pointing
- Thumb Opposition, the coordination between the thumb and other fingers to perform the act of squeezing or holding something while strengthening the 'web space' between the thumb and index finger
- Tripod Grasp, engaging the pincer grasp while the object rests on the middle finger, such as the act of holding a pencil
- Hand-eye Coordination, the act of when hands coordinate with what the eyes see
- Bilateral Coordination, the process of both hands coordinating with each other
- Midline Integration, involves hand dominance and the ability to reach across one's midline that separates the left and right sides of the body (Physiolnq, 2019)



PINCER GRASP



FINGER ISOLATION



TRIPOD GRASP

The daily tasks that use these movements include dressing, managing medication, personal hygiene care, eating and drinking, managing containers (unscrewing jars, removing takeaway lids), managing money, locks, typing, handwriting and meal preparation (Physiolnq, 2019).

The table below, Table 2.1, shows what type of information is available on Government Websites according to each State or Territory when searching for physical recovery and rehabilitation information. .

Information when available focused on the treatment provided by hospital medical staff. This provided a common theme of relying on doctors, hospitals or emergency services to get information. The worst state to gather information from was the Northern Territory as they had no information available on their state government medical website or simply forwarded you to a book, Staying Healthy: Preventing Infectious Diseases in Early Childhood Education and Care Services (NHMRC, n.d.).

State	Meningococcal	Meningitis	Septicaemia / Sepsis
Australian Capital Territory			
New South Wales			
Northern Territory			
Queensland			
South Australia			
Tasmania			
Western Australia			

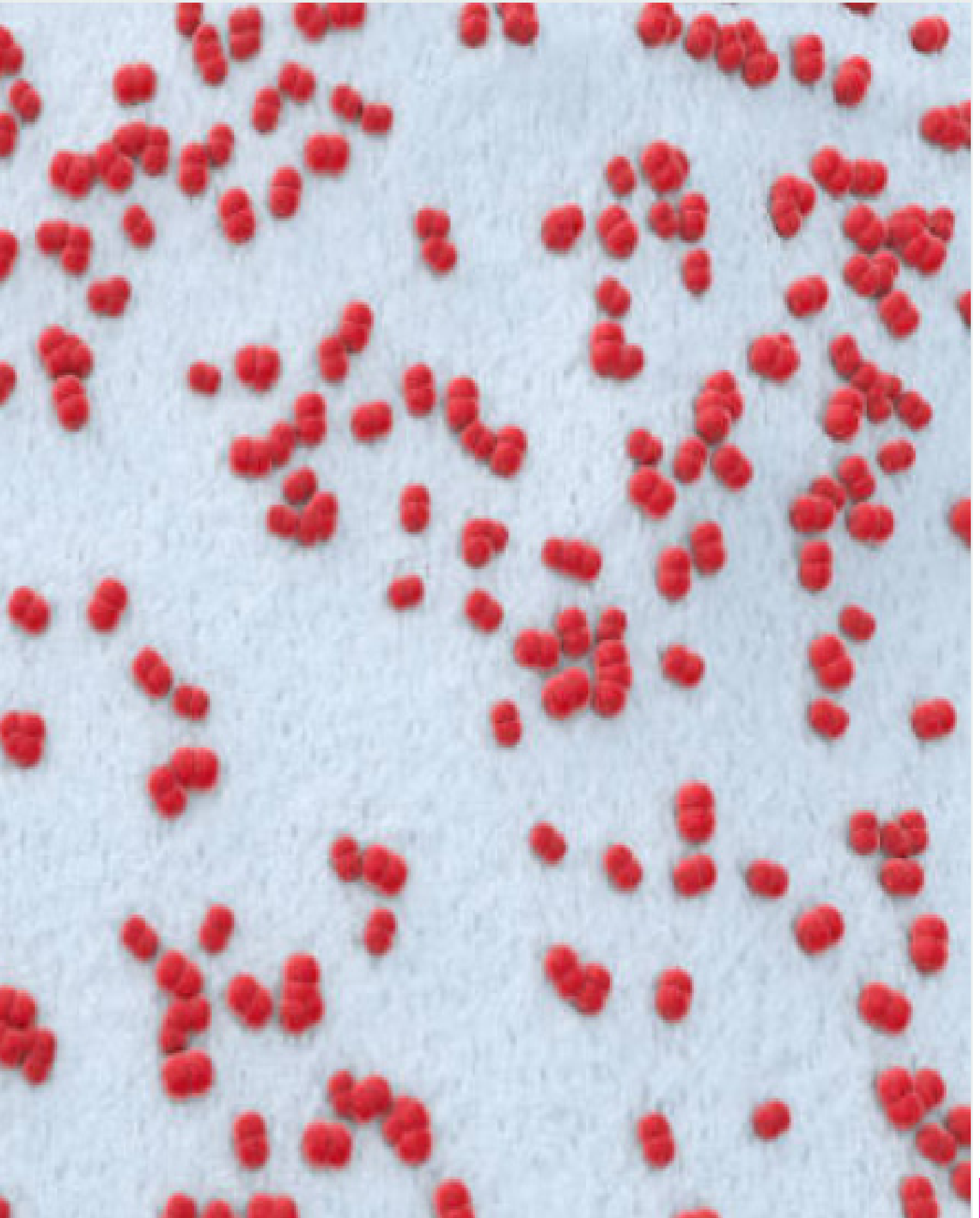
Hospital Treatment	No Specific Treatment	Treatment if Admitted	Other Site
Seek Urgent Medical Treatment	Seek Medical Help from Doctors or Hospital	Unclear / No Information	Detailed Information on Medical Terminology

**TABLE 2.1 SUMMARY OF INFORMATION AVAILABLE FROM GOVERNMENT WEBSITES**



# 03 RESEARCH DESIGN





The research in this dissertation aims to explore the patient's physical recovery and rehabilitation experience after surviving Meningococcal, Meningitis and/or Septicaemia. The purpose of this is to develop recognition of Acquired Brain Injury Patients and the importance of subsequent information, resources, physical recovery and rehabilitation focusing specifically in adults ages 18 to 25 years.

It is the intent of this research to facilitate opportunities to design a product, system or service which may improve the overall rehabilitation experience of patients with an acquired brain injury resulting from Meningococcal, Meningitis and/or Septicaemia. Any solution will focus on the integration of information and resources which are available to the patient.

The literature review gained quality knowledge from academic research and published from reputable sources of patient experience while physically recovering and rehabilitating from acquired brain injuries. The research obtained in the literature review aims to explore what effects Meningococcal, Meningitis and Septicaemia has on a patient's physical recovery and rehabilitation and what tools or experts are available to assist.

### RESEARCH OPPORTUNITY:

Any resolution will focus on improving the physical recovery and rehabilitation process of adult patients aged 18 to 25 years while gaining a better understanding of what it means to have an acquired brain injury (ABI) as an adult. Throughout researching the ABI and diseases opportunities presented themselves, these included;

- A need for adult 18 to 25 years specific recovery and rehabilitation information
- A need for adult 18 to 25 years specific centres to coordinate all aspects of rehabilitation
- A need for more aged appropriate recovery and rehabilitation tools or equipment for adult 18 to 25 years

This research complies with and was approved by the Human Research and Ethics Committee at Queensland University of Technology. All participants signed consent forms to agree to have interviews recorded with their answers used and their personal name used to inform the outcome of the following data.

### RESEARCH QUESTION:

These research opportunities lead to the research question;

What experience do patients go through to physically recover and rehabilitate from an acquired brain injury as a result from Meningococcal, Meningitis and Septicaemia, focusing specifically on mobility training and motor skills?

### METHODOLOGY:

The purpose of this dissertation was to explore what it meant to recover and rehabilitate from an acquired brain injury after Meningococcal, Meningitis and Septicaemia for patients aged 18 to 25 years. The aim was to determine the problem areas within the recovery and rehabilitation journey of mobility training and motor skills. And what opportunities arose for innovation and/or implementation of a product to create a better experience.

Interviews with participants were conducted after an initial survey. As the research topic and age bracket was specific, this resulted in the pool of participants being slim. Three survey responders were suitable for further interviews. From their initial survey the interview participants indicated that they have some communication issues. With this taken into account and interviews were conducted via email with written questions. The participants then had several days to write, review and return their responses. These responses were then received, coded and data categorised.



As this research is aimed to capture qualitative information, semi-structured open ended questions were deemed the most suitable method to capture the full extent of patient experiences. Wilkinson and Birmingham state “There is less flexibility with semi-structured interview. The interviewer directs the interview more closely...though there is sufficient flexibility to allow the interviewee the opportunity to shape the flow of their information.” (Birmingham, 2003).

The questions were planned to understand the context in which the participant conducted their physical recovery and rehabilitation and if there were any other contributing factors to this. The questions in both the survey and interviews were developed to encourage the participant to state issues or their experiences in an in-depth way.

#### **METHODS:**

The goal of this dissertation is;

1. To explore the recovery and rehabilitation experience of patients after sustaining an acquired brain injury resulting from Meningococcal, Meningitis and Septicaemia of patients aged 18 to 25 years
2. To gain a deeper understanding of how acquired brain injuries arise as a result of Meningococcal, Meningitis and Septicaemia.



**PERSONAL EXPERIENCE**



**LITERATURE REVIEW**



**ONLINE SURVEYS**



**INTERVIEWS**



**ANALYSIS**



**RESULTS**

**FIGURE 3.1 RESEARCH STRUCTURE DIAGRAM**

### **PERSONAL EXPERIENCE:**

The primary research is based on personal experience which provided the basic understanding of one patient's recovery and rehabilitation experience after an acquired brain injury resulting from Meningococcal, Meningitis and Septicaemia Serogroup B. The patient had no knowledge of this topic and was not provided further information.

The patient's experience included the understanding of the timeline of events, symptoms and emotions the patient experiencing, medical procedures and recovery and rehabilitation procedures and experiences. Personal experience also provided an understanding of the limited information available for recovering patients. Especially when it came to understand 'why' something had to be done a certain way. Not knowing what the next step was added unnecessary stress that wasn't needed when focusing on the physical recovery and rehabilitation process, and why it is so important to have access to all relevant information and specialists available.

### **LITERATURE REVIEW:**

The second form of research, literature review, was gained from understanding specific information found in medical journals, articles and government and virus awareness organisation websites. The google scholar medical journal publications ranged from articles published in 2007 through to recent article of 2020. Government and virus awareness websites were consistent with information being published in either 2019 or 2020.

### **ONLINE SURVEY:**

The first method conducted was the online survey, where the questions were formed bases on the gaps identified from the literature review and the aims of this study.

The survey contained 17 questions that took approximately 10 to 30 minutes depending on the amount of detail the participant was willing to share. The survey was designed to be concise and easy to read. The survey included multiple choice, short and long open ended written response answer questions. The survey data was collected and managed by Google Forms. The data was then correlated into a working excel spreadsheet where the answers were able to be formatted for easier data refinement (Appendix G).

The data from the completed surveys which was initially stored in Google Forms program allowed graphs and figures to be automatically generated. Allowing the initial results as responses appeared. The data was then downloaded into an Excel Spreadsheet and stored in a remote hard drive for analysis. Multiple choice data were analysed and compiled into pie charts to compare, whereas open-ended data responses were analysed and grouped into themes. This method of collecting data allows the researcher to visually see any trends or themes collected during the survey.

### **INTERVIEWS:**

The second method conducted was interviews, where semi-structured open-ended questions allowed the researcher to gain a better understanding of how a patient viewed their physical recovery and rehabilitation experience both as an inpatient and outpatient. The participants were limited to those who resided in Australia.

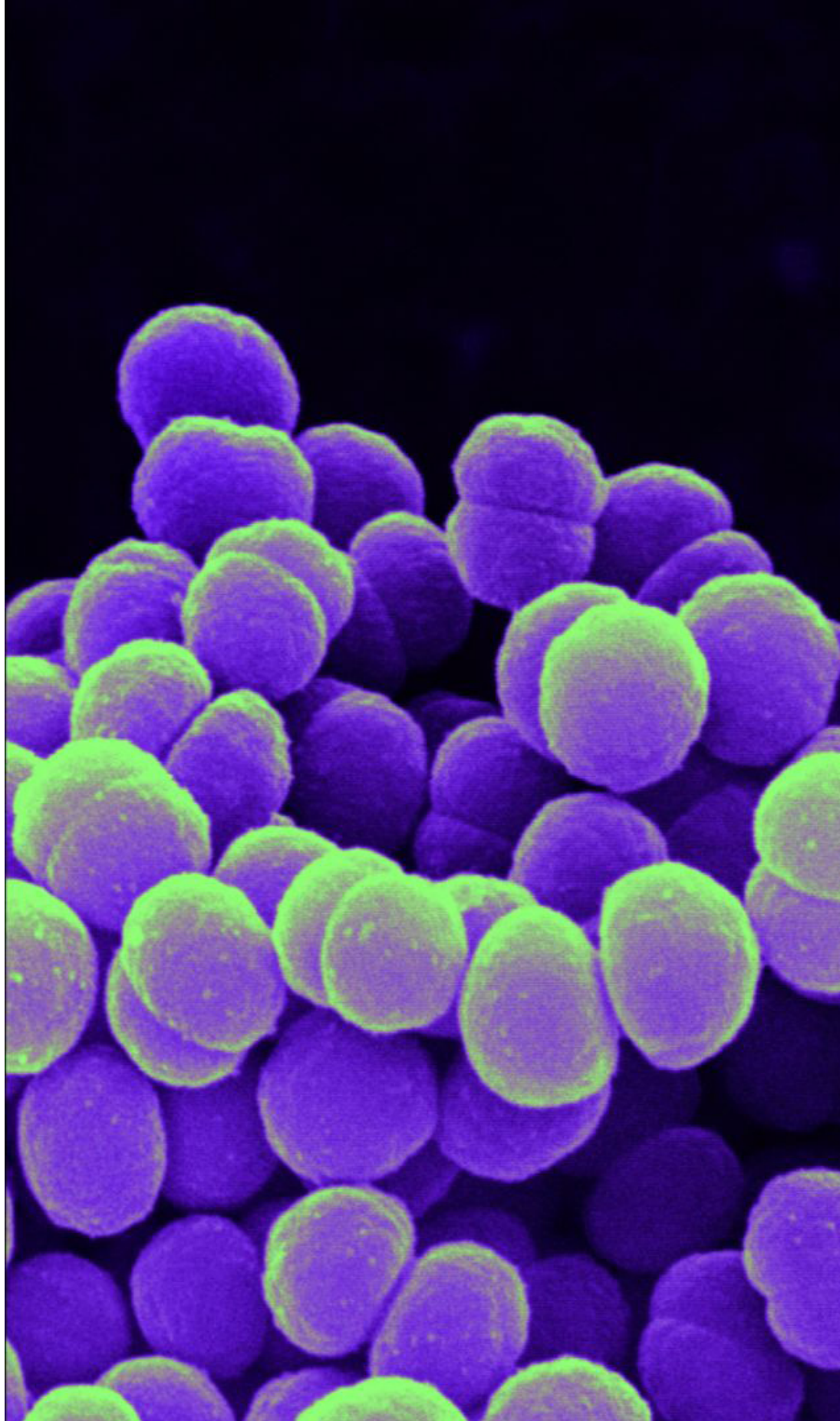
The interviews were conducted in a written format so the participant could take as much time as they needed to express their experiences in a way which they were comfortable in. This resulted in more qualitative in-depth answers.

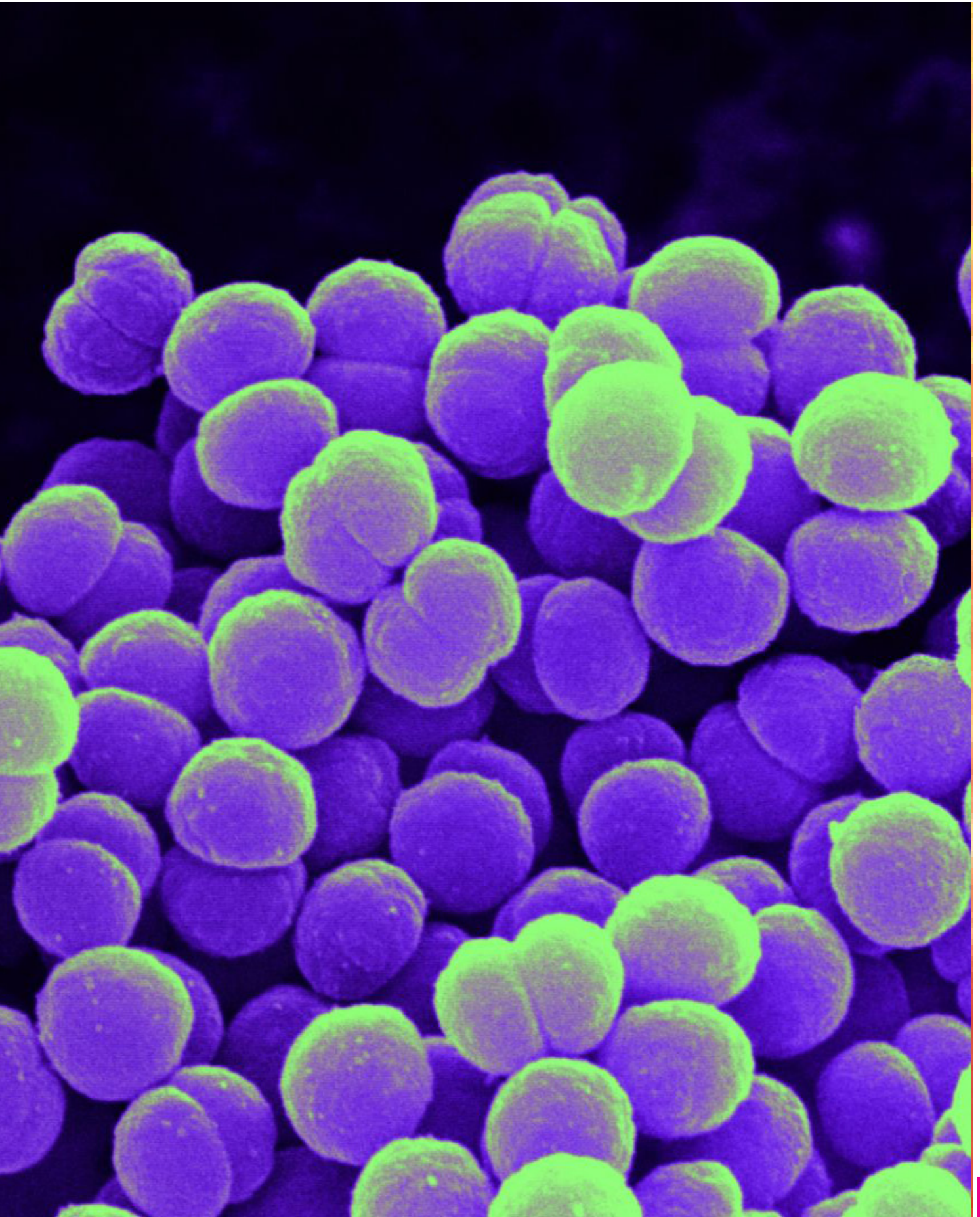
**SUMMARY:**

The sample size of this study was initially limited to the small group of people who have survived Meningococcal, Meningitis and Septicaemia. The sample size was then reduced further by limiting responses to those between the ages of 18 to 25 years, this enabled the most qualitative data results possible.

This research was conducted to develop a more comprehensive understanding of the physical recovery and rehabilitation a patient receives after surviving from Meningococcal, Meningitis and Septicaemia. It was intended that the findings would be used to help ensure the successful integration of a product, system or service.

# 04 ANALYSIS & FINDINGS





### **ANALYSIS:**

A semi structured survey was released on various Facebook, Non- Profit Organisations and Reddit pages. This survey was aimed to gather information from survivors in the preferred age category of 18-25. Even though the target age bracket was 10 to 25, responses was received from patients ages from 1 year to 5r1 years of age. One participant was diagnosed in 1995 and to compare their answers to those who have been diagnosed in the last 5 years showed similar responses. Thirteen survey responses were collected from survivors of Meningococcal, Meningitis and Septicaemia.

These survey responses lead to 3 interviews which were conducted via a non-verbal questionnaire as participants indicated that they have communication concerns and speech/ word selection issues. Written questions were emailed to participants, who then returned written responses to me. This interview process was repeated numerously.

Grounded Theory was used as the foundation of the research construction due to development of theories appearing after the data is collected (Statistics How To, 2020). This theory was introduced in 1967 by American Sociologists Barney G. Glasser and Anselm L. Strauss (Strauss, 1967). The process of Grounded Theory begins with identifying the area of interest while avoiding predetermined theories. Focusing only on the data which is collected using theoretical sensitivity to be aware of subtle messages and meanings in the data (Statistics How To, 2020). Grounded Theory is a framework that gathers qualitative data in a flexible and focused way, which is able to summarise, synthesis and analysis. This approach will lead to the development of new academic understanding.

Grounded Theory can be used to seek out and form a concept from the hidden social patterns and structures from the data collected through continuous comparisons. The initial use of the theory will use an inductive approach to generate codes from the initial data which will lead to more focused collection of data (Grounded Solutions, 2020).

A first pass over a transcript open coding was applied to the first interview responses to develop the basis of the coding scheme. This coding scheme was used to analyse the interviews. Codes and key phrases were pulled out of the texts and compared to see what code and key phrase kept repeating itself.

### **FINDINGS:**

The research set out to explore a patient's physical recovery and rehabilitation by understanding what experience the person had with;

- managing their recovery as an impatient,
- rehabilitation as an outpatient,
- the physical impacts on the body,
- mental challenges the patient and their support system.

Through the analysis of the survey data many interesting points where raised and examined. The discovery of key opportunity areas is expanded on in the following sections. Each area provides knowledge that may prove useful to design a system or product to aid the physical recovery and rehabilitation process.

**SURVEY:**

The raw data collected by the survey showed that the patient’s age can vary but the outcome and responses are similar. The data was collected by age of patient at the time of contracting the disease, from 1 year to 51 years of age, with the most common age group being 18 to 19 years. Refer to Figure 4.1.

**Age of Diagnosis**

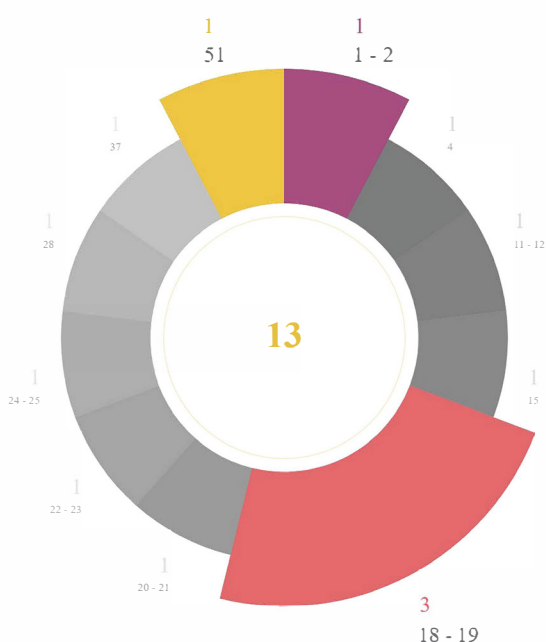


FIGURE 4.1 AGE OF DIAGNOSIS

The time each patient spent as an inpatient varied considerably, from one week to 52 weeks. The inpatient duration is reflected the significant variation of severity of the patient’s reaction to the contracted disease, Meningococcal, Meningitis or Septicaemia. The severity of a patient’s resultant reaction varied from one patient experiencing one specific reaction to another who experienced four reactions. Figure 4.2 indicated patient resultant reactions.

Whilst in hospital when the patient’s physical recovery should have been beginning 54% of patients said they were provided no inpatient physical recovery or rehabilitation, Figure 4.3. Whilst others received slight physiotherapy or routine checks.

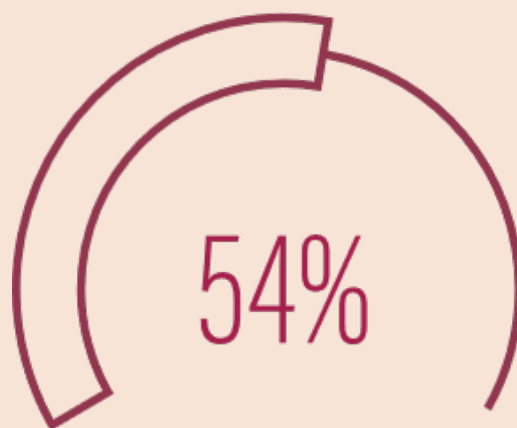


FIGURE 4.3 PHYSICAL RECOVERY TYPES

**Reactions Experienced**

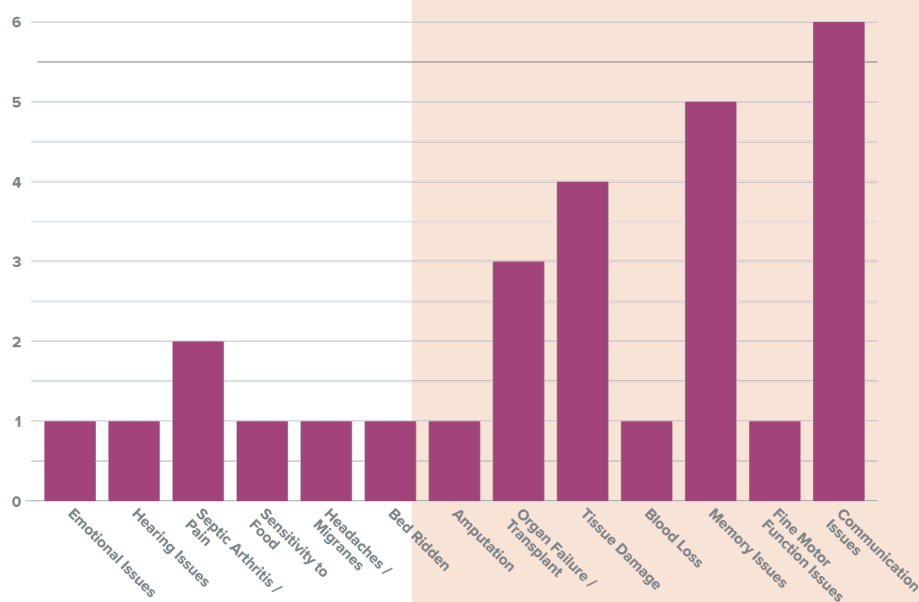


FIGURE 4.2 REACTIONS EXPERIENCED

When the patient's physical recovery improved for them to be transferred from an inpatient to an outpatient status, 46% of patients surveyed said that they were given information about how to further improve their physical recovery or rehabilitation. The majority of those 46% claiming to only receive information for Clinical Psychologists, Occupational Therapists and Physiotherapists, Figure 4.4.

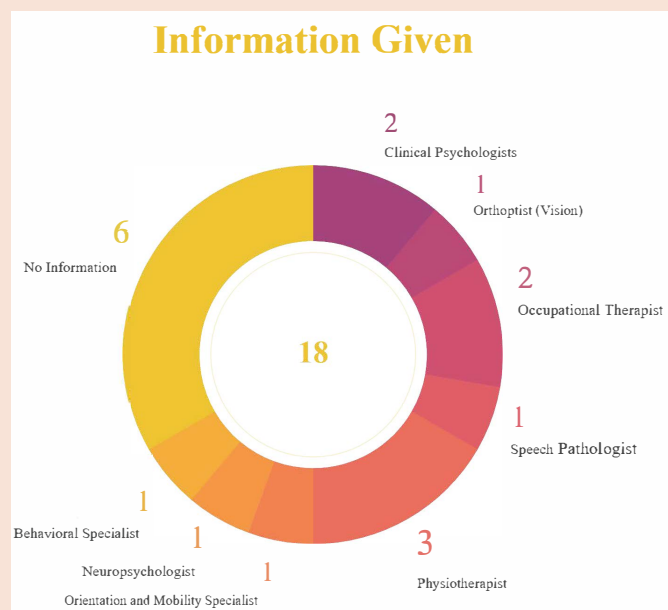


FIGURE 4.4 INFORMATION GIVEN

This led to 62% of the surveyed patients saying that the information that they received as an outpatient was not helpful with furthering their physical rehabilitation or providing information on how to continue their process. This resulted in patients not continuing any physical recovery.

Since the physical rehabilitation wasn't being continued key themes were presenting themselves. Figure 5 shows that the most common struggles the patient stated they had was;

1. Fatigue
2. Strength and Mobility,
3. Reading and writing (Learning),
4. Memory

These 4 key areas provide an opportunity for physical and application base designs.

## Outpatient Struggles

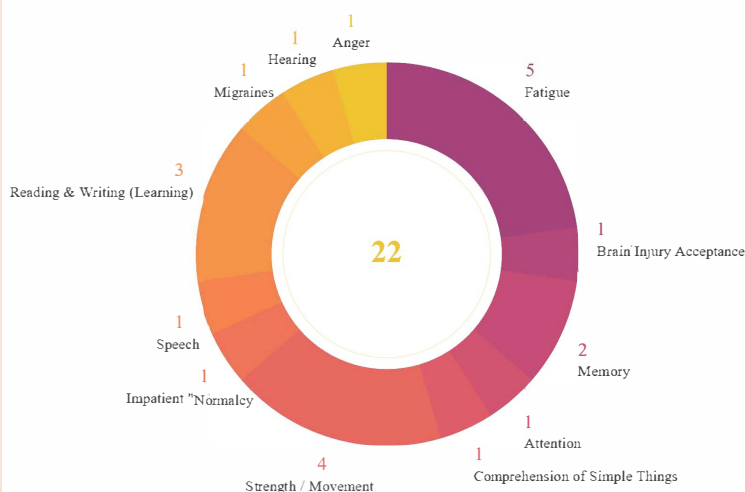


FIGURE 4.5 OUTPATIENT STRUGGLES

The overall physical rehabilitation process outlined via those who were surveyed stated that they were provided;

- Little to no information,
- Basics to relearn how to walk
- Motor skills
- Memory tests
- Altered gym plan for extreme patient with amputations

From the survey the common theme was, if you were a minor case you were released with very little information and was forced to do their rehabilitation independent to professionals.

One survey participant began their physical rehabilitation in 1997 when their parents were their support system. They stated that;

**'PARENTS WERE GIVEN INFORMATION IN HOSPITAL, BUT NO FOLLOW UP APPOINTMENTS OR RECOMMENDATIONS GIVEN'- SURVEY PARTICIPANT 7**



From this statement the information can be assumed to be basic. Other survey participants have stated that they would have liked to have had received more information or direction. More directions or knowledge of a support group/line or community, information on mental health issues, physical recovery activities, recommendations for specialists. The participants have also indicated that they would have liked to receive real world context activities to test whether they are capable to return to work or their studies, and more information on what to look out for in the long term.

From the review of survey participants, initial hypothesis is supported in that available information and support had not advanced or have not become readily available since 1997.

#### **INTERVIEWS:**

##### **Physical Rehabilitation focusing on the Physical Movement:**

The first interview was with Mr Paul Goodfellow, disclosed that he was diagnosed with Meningococcal Septicaemia Serogroup B in August 2013 when he was 37 years old and is nearing the 7th year since his event. Mr Goodfellow is a husband and a father of three with one dog and cat. Mr Goodfellow is a bilateral forefoot amputation (half of the foot removed) (Springer Nature Switzerland, 1992) of both feet, necrotic heels (wound that cannot heal, dead tissue) (Swezey, 2013) and has one tip amputation off one finger.

To regain some use of his feet muscles were removed from his thighs and layered on the heels then covered in skin grafts. Along with the reconstruction surgery Mr Goodfellow had multiple deep wounds, some on his arms, which took months to heal.

Mr Goodfellow says that adapting to tissue damage, even 7 years later, was a long recovery. After the surgery Mr Goodfellow wasn't able to bear any weight for 6 weeks and the affected areas were uncomfortable, red and angry in appearance. According to Mr Goodfellow the pain that is suffered from surgery on his feet has subsided over the years;

**‘I USED TO HAVE PINS AND NEEDLES FROM MY KNEE DOWN BUT NOW IT'S PROBABLY FROM MY ANKLE DOWN ONLY.’**

The sensation of constant burning of the feet has become normal, Mr Goodfellow says the most "normal" part of his day is when he wakes up as there is no tingling and no pain.

In the beginning of physical recovery added additional toll from the loss of muscle on his body. The initial strength training was difficult and draining as Mr Goodfellow couldn't lift a kilogram, had the shakes and couldn't use a knife or fork (motor control issues). Physical recovery for Mr Goodfellow consisted of gym daily with two sessions Monday to Friday and one session per day on Saturday and Sunday. This was upheld throughout Mr Goodfellow's 108-day hospital stay.

After 6 months Mr Goodfellow was allowed to return to work with crutches to assist with mobility as he wanted to return to as normal as possible life. This helped Mr Goodfellow with his mental rehabilitation. "Normal" is defined by Mr Goodfellow as;

**“..GOING BACK TO WORK,... SPENDING TIME SHOPPING WITH MY WIFE, GOING OUT TO DINNER, OUT ON THE WEEKENDS, JUST ANY NORMAL ACTIVITY THAT I DID BEFORE...”**

Wanting to return to “Normal” was a goal for Mr Goodfellow as he was released from hospital in a wheelchair which he wasn’t used to and wasn’t normal. With Mr Goodfellow knowing that he wanted to return to “normal” he would use household items and integrate them into his physical rehabilitation program.

**“I WOULD SWEEP AND MOP THE FLOOR USING THE MOP OR BROOM TO LEAN ON WHILST STILL DOING SOMETHING,..”**

Mr Goodfellow’s physical rehabilitation gym sessions reduced to three to four sessions a week until given the all clear four months later. Mr Goodfellow did note that a bike was good for aerobic exercise, cardiovascular conditioning as an increase heartrate and oxygen level (Chertoff, 2020), which was beneficial with the ability to bear no weight. Strength training plays a crucial role in physical rehabilitation as the upper body helped Mr Goodfellow to get up and about. Such as, getting out of bed and out of a lounge chair.

Mental health played a huge role in Mr Goodfellow’s physical recovery and rehabilitation. Mr Goodfellow reached out to a physiologist but his experience wasn’t the best.

**“I DID MEET WITH A PSYCHOLOGIST ONCE BUT WHEN I NOTICED HIM GLANCING AT HIS WATCH IN THE FIRST 10 MIN OF A 45 MIN APPOINTMENT, I GOT THE FEELING HE WASN’T THAT INTERESTED...”**

Mr Goodfellow stated that he would rather go to his GP and “blurt out how he was feeling and understand that this was normal”. Goodfellow preferred the GP as they were a good listener and weren’t more interested in their watch. Along with his GP Mr Goodfellow’s wife and his children were fundamental to Mr Goodfellow.

Mr Goodfellow stated that he would rather go to his GP and “blurt out how he was feeling and understand that this was normal”. Goodfellow preferred the GP as they were a good listener and weren’t more interested in their watch. Along with his GP Mr Goodfellow’s wife and his children were fundamental to Mr Goodfellow.

Mr Goodfellow’s physical recovery and rehabilitation experience is based on physical movement which is significantly different to a patient whose physical recovery and rehabilitation is focused on mental and speech capabilities.

### **Physical Rehabilitation focusing on Mental Capabilities, Speech and Dexterity:**

Mr Daniel Hawes was a 20-21 year old in 2018 who suffered a sinus infection that migrated through his bloodstream to form a brain abscess. A brain abscess is a collection of fluid that develops as a reaction to an infection (Brazier, 2018). Mr Hawes is currently in his second year of recovery and is studying a Bachelor of IT at Queensland University of Technology.

Mr Hawes’ physical and rehabilitation focused on his mental capabilities and speech. Physical movement was touched briefly in the initial inpatient recovery. Relearning to walk for Mr Hawes was with a student physical therapist that assisted him with an IV pole for stabilisation. In the first few weeks of recovery Mr Hawes had a lot of issues communicating with others. Speaking was difficult, as well as word selection.

**“I’VE LEARNT TO BE QUIET, CALM AND TO SPEAK WITH MEANING AND PURPOSE TO AVOID HAVING TO REPEAT MYSELF AS WELL AS AVOID SPEAKING WHEN I’M NOT REQUIRED TOO”**

Mr Hawes was able to reduce the repercussions of his brain abscess with speech therapists. According to his mother Mr Hawes stated that “if someone who has never met him before would never notice his speech difficulties, he would appear to be someone who speaks slowly”. Mr Hawes’ family and friends were able to discern a difference in his speech pattern.

Mr Hawes has said that he has speech communication issues which he has separated into five categories:

1. Word Synthesis
2. Stutter
3. Trouble Speaking
4. Forming Words
5. Word Difficulty

Word Synthesis is defined by Mr Hawes as the “synthesising of the word in his head and getting it out”. A coping mechanism developed by Mr Hawes is to navigate his speech around the word he cannot remember. An alternative to this, developed with a speech therapist, was to describe the word, describe the definition, what it does and what it relates to. This according to Mr Hawes helped him greatly to find the correct word.

Stutter or ‘Tripping Over’ specific words. For Mr Hawes, this is common when words have one sound in the word has a very similar mouth shape to form the next sound.

Trouble Speaking when rushed has affected Mr Hawes the most. This problem seems to be linked to the emotions Mr Hawes is feeling in the conversation. For example, when he feels an immense sense of pressure or the person, he is speaking to seems to be really rushing for him to get his words out, he won’t be able to speak. Mr Hawes uses the analogy of a car crash to explain this;

**“...IT’S LIKE MY BRAIN IS A ONE WAY STREET, AND I TRY TO RUSH WORDS OUT, THERE IS A BIG CAR CRASH AND I HAVE THE WORDS/THE SENTENCE IN MY HEAD BUT I CAN’T PUSH IT DOWN THE ‘STREET’ TO VOCALISE THEM.”**

Forming words differs to synthesising words or stuttering, this is most common when Mr Hawes is trying to express an opinion in a rushed way or if he is speaking for a long period of time. Mr Hawes describes this as if his mouth were to get tired and trail off on the end of some words.

The last category is Word Difficulty. Mr Hawes stated that some words are just harder to pronounce, they are not necessarily bigger or more complicated its often how the words are formed in the mouth. Mr Hawes describes this as “having lost some of his word forming dexterity somehow”.

Mr Hawes also had communication issues when it came to his fine motor functions. This resulted from reduced agility in his fingers which effected the speed and accuracy in which he typed and the speed and dexterity of his handwriting. Mr Hawes has stated that handwriting is more difficult as his hand has the tendency to get sore/fatigued quicker which results the reduced ability he has to maintain neatness.

Mr Hawes short-term memory, reading and writing comprehension has also been affected. The short-term memory was the hardest to adapt to according to Mr Hawes as it wasn’t immediately noticeable until he was an outpatient.

**“I STARTED TO POINT OUT THINGS TO MY MOTHER THAT I THOUGHT I HADN’T SEEN BEFORE WHICH IN FACT I [HAD] SEEN THEM.”**

A physical and speech therapist worked with Mr Hawes to improve his memory, using online activities, as a result of this he keeps a small journal on him that he writes down anything that he doesn't want to forget. Similar to the memory activities online Mr Hawes used online sources that targeted non-English speaking individuals to improve his reading and comprehension of the English language. This also contributed to his memory training.

### LIMITATIONS:

The sample size of the data collected within this study is notably small, therefore there is a probability of reduced accuracy in representing all survivors of Meningococcal, Meningitis, Septicaemia and the like. However, since the research has been developed with the inclusion of Grounded Theory, the purpose was to generate new theories through deeply analysed qualitative data. This outcome has still been achieved regardless of the small sample size.

Participants have been sort out through social media platforms, Facebook and Reddit, focusing on those that live within Australia. As survivors are limited, those who participated in this study range from various backgrounds and ages. those who have received an acquired brain injury in another situation that isn't after the Meningococcal, Meningitis and/or Septicaemia diseases, but have similar recovery and rehabilitation. This led to the inclusion of a participant who had developed an acquired brain injury from another source outside my specific area.

All data collection and interviews were conducted online and not in person. This is complying with the restrictions of the COVID-19 pandemic. This method also worked well for those participants who have communication issues, typed responses were preferred.

### SUMMARY:

The research aimed to explore the experience of patient's physical recovery and rehabilitation, from an acquired brain injury as a result of Meningococcal, Meningitis and Septicaemia. Focusing on the importance of physical movement and at home/independent methods. It is intended that the findings would be used to inform the design decisions for a product or system related to the physical recovery and rehabilitation focusing on an independent or at home approach.

The management of information that is available to the patients is limited but not necessarily provided to the patient. The system that is currently in place has shown to have not improved since 1997, with patients leaving the hospital with very limited or no information on how to conduct or progress their recovery or rehabilitation further.

The patients interviewed had vastly different physical recovery and rehabilitation experiences. The physical movement which was focused on which were indicated by the interview participants was;

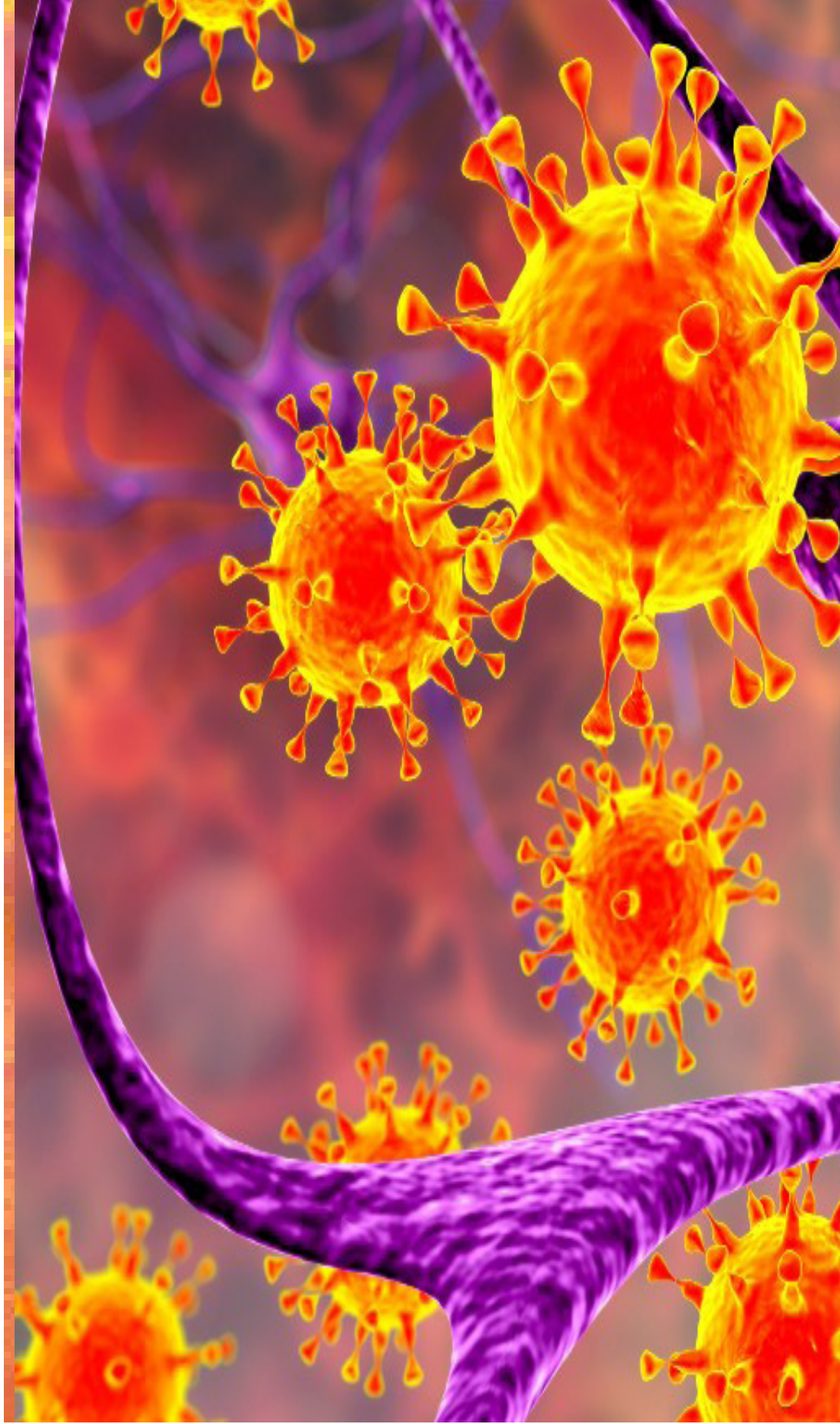
- Mr Goodfellow's physical recovery was focused on the physical movement, which is how to walk, move his body from sitting to standing and the ability to hold weighted objects not necessarily mental;
- Mr Hawes' physical recovery was focused on the physical movement of gaining strength when walking and fine motor skills such as the muscle memory of writing. With his acquired brain injury, the ability to format words, concentrate for long periods of time were compromised.

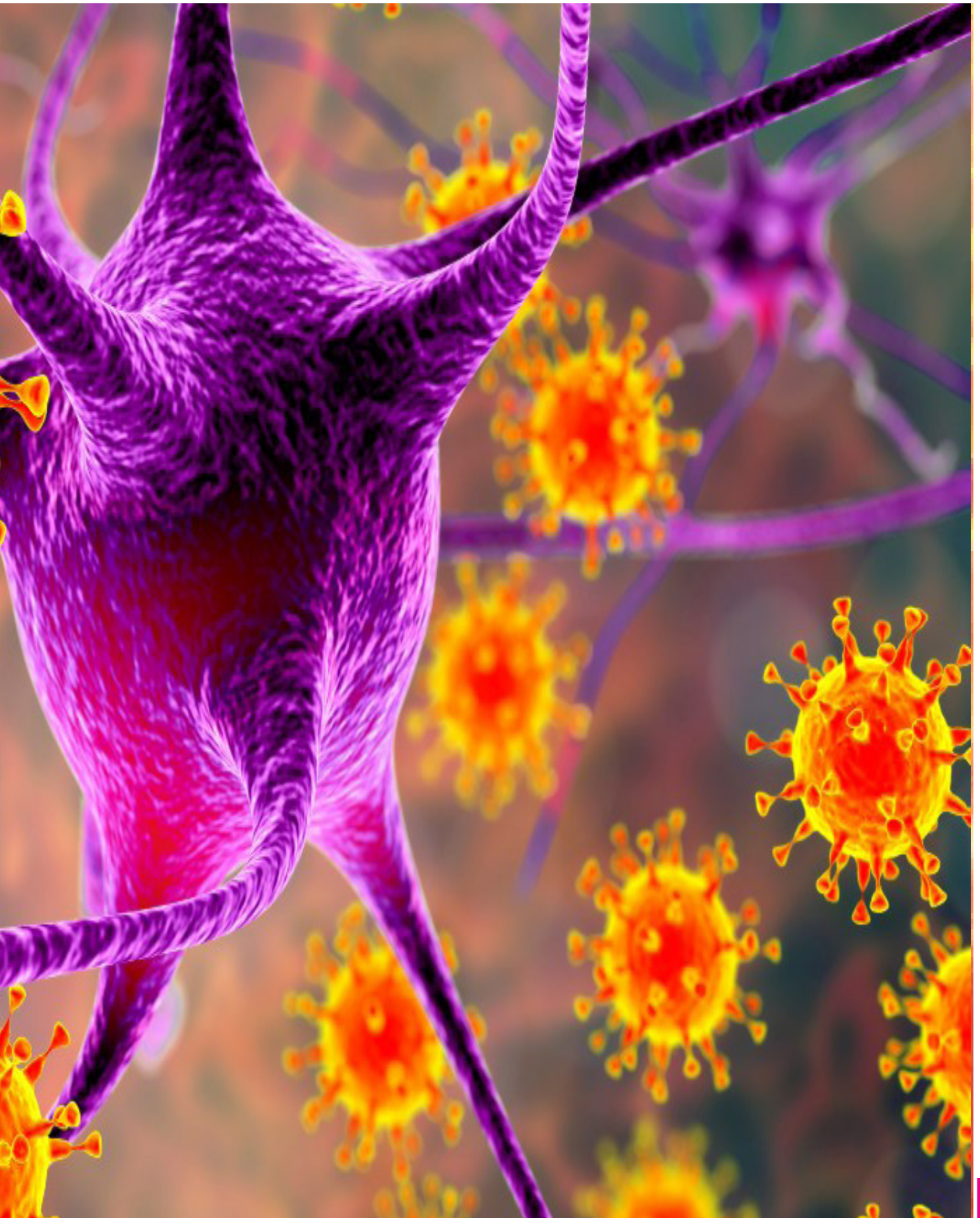
The differing research outcomes has confirmed that physical and mental require different methods to assist in identifying any deficiency from the acquired brain injury. Physical issues are more readily apparent, but the mental restrictions have to be sought out with specific tests or activities. It is easier to recognise and improve the physical issues than it is of mental.

These findings have shown three areas in which a product, system or service can be implemented to better the experience;

1. Patient Orientated
2. Parent, Partner or Guardian Orientated
3. Community Orientated.

# 05 DISCUSSIONS & RECOMENDATIONS





## **INTRODUCTION:**

This research is aimed to develop a thorough understanding of the personal experience patients face for those who have survived from Meningococcal, Meningitis and Septicaemia. The experiences focused on are those which happen with or around physical recovery and rehabilitation. With the research into the medical information available into the recovery and rehabilitation process for those aged 18 to 25 years, has shown that very limited information and resources are available. It was also shown by survey participants that the way the medical industry shares its resources has not changed since 1997.

This paper also aims to address the challenges that occur from individual medical recovery and rehabilitation plans. The analysis and combination of these findings were used to develop the design recommendations for a product, system or service that may be integrated to support and provide a better experience for patients who have survived from Meningococcal, Meningitis and Septicaemia as well as those who have an acquired brain injury.

The literature surrounding Meningococcal, Meningitis and Septicaemia presented three key areas where there was either lack of information or resources all together. Primarily, there is a separation between professionals within the medical industry and patients and guardians. Also, there are challenges around the personalised individual recovery and rehabilitation plans each patient receives. However, there is little understanding on how to recognise signs that show areas of requiring further recovery and rehabilitation.

The three areas in which a product, system or service can be implemented to better the Physical Recovery and Rehabilitation of Meningococcal, Meningitis and Septicaemia experience are; the Patient, the Parent, Partner or Guardian and the Community.

## **THE PATIENT:**

The Patient is the main user to consider when developing ideas for a product, system or service as they will be the primary user. The primary user is defined as “someone who interacts with the system .... in direct contact with the system interface and this is usually most affected by it” (Tenhue, 2016). Meaning that anything that is designed must benefit the patient’s physical recovery and rehabilitation experience first before benefitting other user areas.

## **THE PARENT, PARTNER OR GUARDIAN:**

The Parent, Partner or Guardian in some cases will be the initial user if the Patient is unable to use the product, system or service. Otherwise they will be the secondary user to design for. A secondary user is defined as someone who “does not directly interact with the user interface of the system but is still affected by it” (Tenhue, 2016).

## **THE COMMUNITY:**

The Community is defined as anyone who is affected by Meningococcal, Meningitis or Septicaemia or those who are suffering from an Acquired Brain Injury.

## **RECOMMENDATIONS:**

This section outlines design suggestions that could be implemented into the physical recovery and rehabilitation experience. These design suggestions have been informed by the research findings of this dissertation. One of these design suggestions will be used as the basis to develop either a product, system or service which aims to better the patient’s physical recovery and rehabilitation from Meningococcal, Meningitis or Septicaemia.



### OPPORTUNITY 1 - INFORMATION & COMMUNITY APPLICATION:

The smart application is defined as an application which can be downloaded on any smart device e.g. phone or tablet. This smart application can help not only the Patient, primary user, but also the Parent, Partner or Guardian of the patient. This smart application is a service which the user can interact with to either gain accredited information about the background of Meningococcal, Meningitis, Septicaemia or an Acquired Brain injury to help better understand what has happened. This smart application can also be adapted for similar scenarios such as stroke patients as they can also develop an acquired brain injury. This application can also be used to connect the user with professionals that are located in the patient's locality who can aid in the Physical recovery and rehabilitation process.

This smart application can be used by the Parent, Partner or Guardian if they require additional information about what is happening. Whether it is about the diseases or what care is required, at a time which is convenient or when they are ready for it.

The Community aspect of this application begins to present itself with users communicating through the app, either anonymously or named, to help those who are beginning their journey. This can also be a platform to encourage others in their physical recovery and rehabilitation journeys by sharing what helped them or what suggestions they have to improve the experience.

The advantages of the application;

- Readily available accredited information which the user can access.
- Help locate and contact Medical Professionals, hotlines who specialise in either Meningococcal, Meningitis, Septicaemia or Acquired Brain Injuries.

- Safe platform to communicate with others who are or have gone through the physical recovery and rehabilitation process.
- Provide information to support organisations

### LIMITATIONS AND CONSIDERATIONS:

The Information & Community Application would need to have access to current, credited information which the user can access readily. The information can be collected through medical journals, non-profit organisations or medical professionals. The medical professionals would also have to be willing to allow the application to house and distribute their professional information. This can be achieved by partnering with an Allied Health Association or health departments to help with keeping the information up to date and relevant. The user of this application may not have access to compatible technology e.g. phone or tablet.



FIGURE 5.1 OPPORTUNITY 1 - INFORMATION & COMMUNITY APPLICATION

### OPPORTUNITY 2 - ACTIVITY / CARE BOX:

The activity box can help not only the Patient, primary user, but also the Parent, Partner or Guardian of the Patient. This activity or care box is a product which the user can interact and use objects to interact with either by themselves or with visitors. This activity or care box can help those who are recovering from Meningococcal, Meningitis and/or Septicaemia by;

- Providing a thicker pen and notebook, with larger line spacing, to begin regaining fine motor skills
- Dot to dots can also be used to increase fine motor skills
- Physical calendar and binder to house all important documents to help organise and time manage appointments
- Colour by numbers activity book to determine the ability to follow instructions
- Reading and writing activities to gauge if the patient has any comprehension issues
- Find a word and cross words to help identify specific words
- Card games such as Uno, solitaire, go fish and memory to improve or gauge if the patient has any memory issues.

This activity and care box can also be used to connect the community with those who are beginning their recovery and rehabilitation process by compiling the content of the box.

The advantages of the activities and care box;

- early identification and acknowledgement of potential issues
- activities which you can integrate friend or family to incorporate quality time

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- early identification and acknowledgement of potential issues

- activities which you can integrate friend or family to incorporate quality time

### LIMITATIONS AND CONSIDERATIONS:

The solution would need to be universal and non-gender specific. The complexity of the activity and care box would need to be considered for the vast range of the patient's recovery and acquired brain injury status. The activities will require endorsement from allied health professionals. This Activity and Care Box will also need to have select options aimed at certain age grounds or themes, such as adult female, flowers, gardening, motor vehicles, etc.

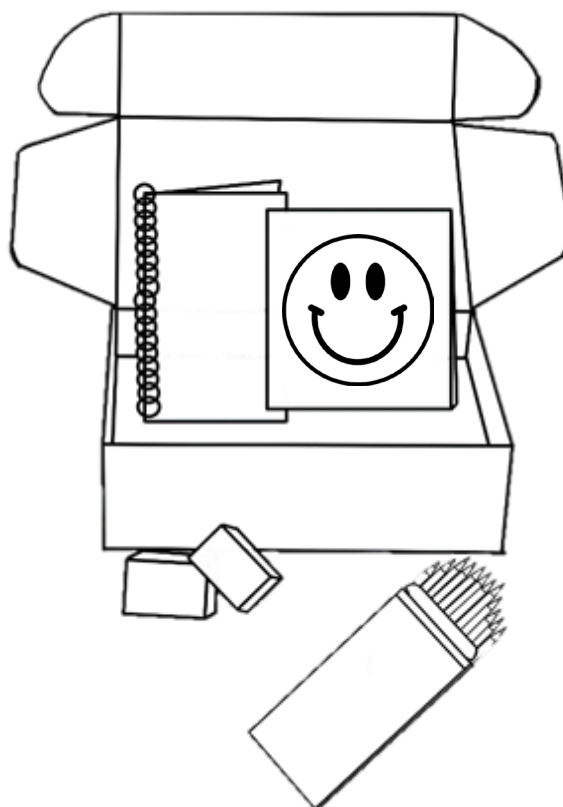


FIGURE 5.2 OPPORTUNITY 2 -  
ACTIVITY / CARE BOX

### OPPORTUNITY 3 - INITIAL COMMUNICATION APPLICATION:

This communication application can help the Patient, primary user, communicate with the Parent, Partner or Guardian and Hospital staff. This communication application is a service which the user can interact with to either gain independent speech or use to read out loud documents. This application can be used to improve the patient's speech, communication skills and word recognition.

The advantages for this application;

- Readily available for the user to access
- Help the user identify and improve communication issues
- Can be used as a learning tool to gain better language comprehension

### LIMITATIONS AND CONSIDERATIONS:

The solution would need to be compatible for both android and apple products for phone and tablet use. This solution would also need to have a website alternative if there is not a smart device available. The application will need to vary with the level of communication and comprehension the patient would need. The navigation around the application would need to be simple but engaging. The user of this application may not have the technology of a phone or tablet readily available to them.

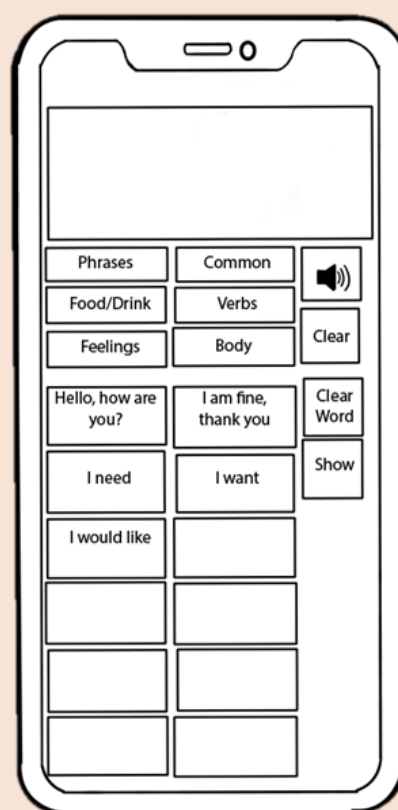


FIGURE 5.3 OPPORTUNITY 3 - INITIAL COMMUNICATION APPLICATION

# 06 PROPOSAL





## INTRODUCTION:

Any injury resulting from diseases such as Meningococcal, Meningitis and Septicaemia can result in physical and mental difficulties. Survivors of these diseases require supporting information to assist in physical and mental recovery and rehabilitation, however finding and acquiring this information is difficult.

The intent of this project is to develop a better, more refined process to assist in the physical recovery and rehabilitation an acquired brain injury resulting from Meningococcal, Meningitis and Septicaemia. This project has a primary focus on physical movement and at-home/independent methods for patients.

For this product, system or service to successfully capture this opportunity, designers should consider the three key findings of this paper. Firstly, described in the recommendations and discussion but then summarised by the design objectives, these findings revolve around the patient's physical recovery and rehabilitation, and the use of human centred design strategies or coping mechanisms.

The following design proposal addresses these findings and suggests how they could be applied into a design using physical recovery and rehabilitation guides for patients. .

## DESIGN INTENT:

To develop a product, system or service relating to the physical recovery and rehabilitation, primary focus being Meningococcal, Meningitis and Septicaemia patients, to simplify and improve the patients journey of recovery and return to everyday life.

## OBJECTIVES:

Project objectives have been determined from research responses and will provide direction to the final design. The final objectives are;

- The design should help to support a patient and parent or guardian through the physical recovery and rehabilitation process

- This solution should encourage a positive independent recovery and rehabilitation experience
- The final design is to incorporate human centred design

## PROPOSAL JUSTIFICATION:

Meningococcal, Meningitis and Septicaemia is recognised as a disease that can cause traumatic and lifelong injuries or effects to a person's life. Whilst these diseases are common the outcomes a patient can experience will vary from patient to patient. There is informative information available on these diseases, however the information relating to possible recovery and rehabilitation programs is non-existent and possibly unchanged since 1997.

Outlined in the objectives, this study discovered three areas of opportunity. These can be leveraged in the development of a new Meningococcal, Meningitis and Septicaemia product, system or service for the patient, guardian or community. Introducing a design solution that addresses the objectives will not only support the physical recovery and rehabilitation of the patient, it will also give guidance for symptoms, questions or queries by creating a new avenue to find information or collect resources.

## CONTEXT:

The target audience for this solution creates an interesting context for the design to be set in. Evidently, the initial physical recovery and rehabilitation is achieved in a hospital setting but the majority of this is continued as an outpatient in the persons home. The target patient group is between 18 and 25 years of age. These patients will vary depending on their physical abilities, age, interests and occupations meaning they will all be considered a part of this project. Their similarity comes in their common experience with these diseases which is a difficult and jarring experience. One that is difficult for outsiders to understand.

This design proposal is contextually based within the whole of Australia. This is of the interest of the proposal since this sets the legal and legislation constraints on any products, systems or services designed. Particularly since the product, system or service revolve around the medical industry.

### **CRITERIA:**

To achieve the aims and objectives that have been discussed previously, the design development process should be guided by a series of criteria. These criteria have been determined by Don Norman's *The Design of Everyday Things* as the seven fundamentals of design (Norman, 2013). These fundamentals are, discoverability, feedback, conceptual model, affordances, signifiers, mappings and constraints (Norman, 2013). This may be extended or advanced on throughout the design process.

### **FUNCTION:**

The design should improve the physical recovery and rehabilitation experience for the patient, parent, partner or guardian or community throughout the context on inpatient to outpatient.

### **ACCESSIBILITY:**

This solution must cater to a wide variety of users within the context of Meningococcal, Meningitis or Septicaemia survivors. This should include people from a wide range of abilities and occupational backgrounds.

### **FEEDBACK:**

Appropriate feedback will be needed in areas such as physical recovery as an inpatient, physical recovery as an outpatient, reading and comprehension, speech, fine motor skills or other activities which will improve the patients experience. In physical solutions this might include affordances or signifiers. Any digital solutions will require a strong user-friendly interface and user experience development will be needed to achieve this.

### **DISCOVERABILITY:**

The final design should have a strong discoverability and understandability for every solution whether physical, systematic or service. This will be crucial to the designs success and will require user research and testing to guarantee a well-received outcome.

### **CONTEXT:**

The context the design should adhere to the age category of 18 to 25 years old, primary user, and parents, partners or guardians, secondary user. These users will vary in age, gender and occupation but will reside within Australia. The setting which the product, system or service will be used is either in a hospital or residential context.

### **SUSTAINABILITY:**

Any digital elements of the design should be developed in a flexible manner that allows the element to be updated as new information, professionals, products or services become available. Any physical solutions should have consideration of the context. This ensures that the product will be designed to be durable. In both of these cases user support services should be considered for product, system or services to ensure that the solution will continue to have relevance.

**SCHEDULE:**

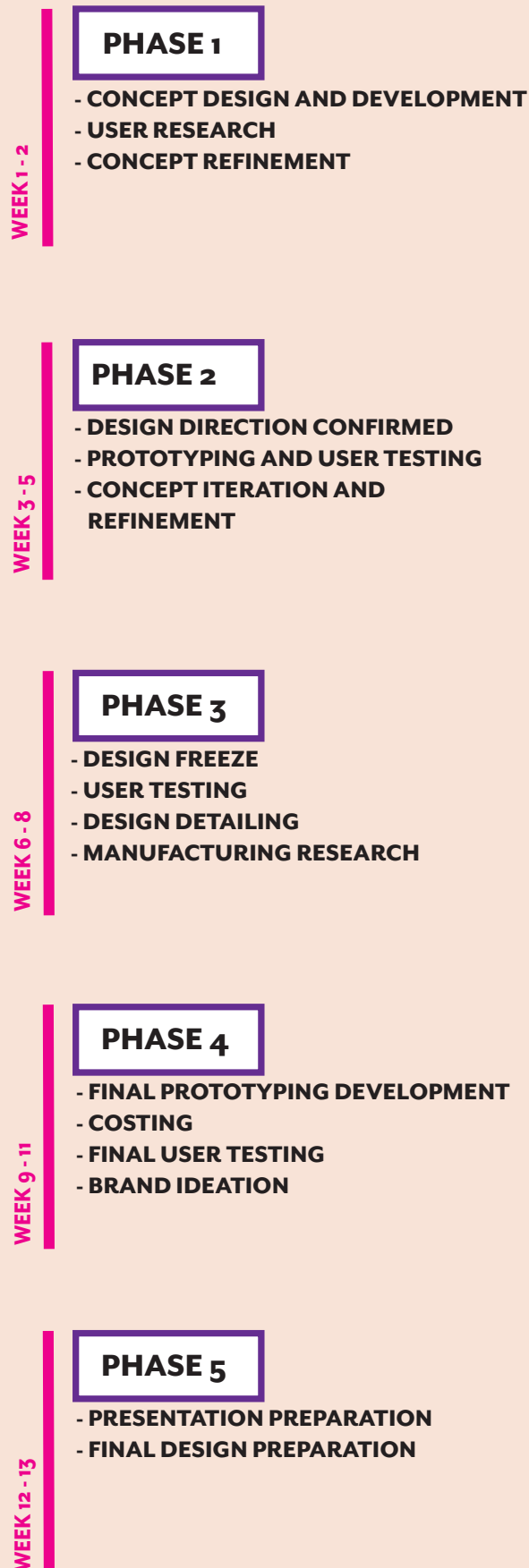


FIGURE 6.1 SCHEDULE DIAGRAM





# 07 JUSTIFICATION







- You've Got This...., \$159.00



You've Got This.....

- Men's Hospital Get Well Soon, \$155.00



Men's Hospital Get Well Soon

- Men's Hospital Hamper, \$149.00



Men's Hospital Hamper

- Men's Hospital Entertainer, \$119.00



Men's Hospital Entertainer

- Rest Easy Care Package, \$135.00



Rest Easy Care Package

- Rest and Recover Care Package, \$142.00



Rest and Recover Care Package

- The Ultimate Care Package Hamper, \$349.00



The Ultimate Care Package Hamper

- Benji Koala New Baby Gift Box, \$99.00



Benji Koala New Baby Gift Box

- Recovery Entertainer, \$138.00



Recovery Entertainer

- The Ultimate Entertainer, \$155.00



The Ultimate Entertainer

Feel Better Box have two products, The Ultimate Entertainer (\$155) and the Recovery Entertainer (\$138), that are similar to Bounce Back. These boxes include products such as:-

- Solitaire
- Card Game - Brain Teasers
- Cheesy Jokes
- Two mini games books
- Book
- Mindfulness Colouring Book
- Faber & Castell 24 Colouring Pencils and Sharpener
- Gift Card

These boxes are a nice gift idea if you wanted to gift something besides 'get well' flowers. These products will last longer and can potentially serve a purpose in a hospital setting.

Research has shown the benefit of Game-Based Rehabilitation with stroke patients. As strokes serve as a comparison to an acquired brain injury this concept has been applied to the

Bounce Back system. An article which was published in the Wolters Kluwer Medicine Journal, What Do Stroke Patients Look for in Game-Based Rehabilitation: A Survey Study stated that "one third of stroke patients actually perform recommended exercise at home, because of the repetitive and mundane nature of conventional exercise" (Ya-Xuan Hung, 2016).

The journal also states that "Game-based rehabilitation systems have the potential to encourage patients continuing rehabilitation exercises at home". This premise has been applied when developing the Bounce Back system with the inclusion of activities and games which benefit the healing of an Acquired Brain Injury and can promote early detection of areas of concern. The game-based rehabilitation can promote appealing and personalised motivation to continue patient recovery and rehabilitation process out of a hospital environment.

### CONTEXT, SYSTEM & SCENARIO:

#### PEOPLE:

The focus of this topic has been to improve the physical recovery and rehabilitation of a patient with an acquired brain injury from either Meningococcal, Meningitis or Septicaemia. As the effects these viruses could have on a patient varies, providing a way to gather and deliver relevant information in a format that best suits the patient, parent, partner or guardian is crucial. A patient's reaction to the viruses plays a huge role in the recovery and rehabilitation process, as the severity of mental and physical conditions develop from this.

#### STANDARDS:

The redesign of the information delivery platform and early detection activities meet Australian Standards of 2020. As this system isn't designed as a medical device it abides with the Therapeutic Goods Act 1989 as the application will fall under the health and lifestyle category. The Therapeutic Goods Act 1989 states that "The TGA does not regulate health and lifestyle

apps and software that do not meet the definition of a medical device” (Australian Government, 2020).

This application is a source of information and communication and the Bounce Back Box is designed to begin the process of regaining brain movement, it does not diagnose a patient. Bounce Back falls under the health and lifestyle category of the Therapeutic Goods Act 1989.

**ACTIVITY:**

The Bounce Back system has two separate purposes:

- 1) Access to relevant and current medial information and communication
- 2) Initiate the regaining of brain function

The application serves as a platform to distribute current and relevant information in a format and time that best suits the patient, parent, partner or guardian. This platform also

provides links to relevant community chat rooms. These chartrooms are separated into different categories such as; patients, parents or partners. This allows the person to feel included in the wider community and not so alone in the recovery and rehabilitation process. These links are provided should the patient or their carer choose to make the connection.

The Bounce Back Box serves the purpose of providing information the carer may need in the initial stage of the patient’s hospital visit, reducing the unnecessary stress the situation brings and to manage provided information. Once the patient is ready to take charge of their recovery the Bounce Back Box can become theirs. The activities which are included can help the patient to initiate the regaining of brain function. The activities also serve the purpose of encouraging social interaction and the reduction of stress.



**FIGURE 7.1 BOUNCE BACK BOX**

**CONTEXT:**

The Bounce Back system will be used initially in a hospital setting then transition to the home setting. This system is designed to work with non-profit organisations, medical journals and the government. The product is designed to be stored in the hospital in small flat pack units and when a patient is admitted the volunteer staff will assemble the box.

The assembled box will then be delivered to the parent, partner or guardian by the social worker. The social worker's priority is to look after the family and take unnecessary pressure off the carer so the family can focus on the patient. The social worker does all the behind the scene

stuff that not everyone is aware of, making sure the correct forms are signed, finding close accommodation and even provides counselling.

Once the patient begins their recovery and rehabilitation process the Bounce Back system can be utilised by the patient. The patient will be granted access to the application and given the Bounce Back Box to begin using all that is contained within it. This box will be beneficial once the patient and carers begin to have visitors as it can serve as a way to encourage social interaction.



FIGURE 7.2 ICU HOSPITAL ROOM



## DESIGN PROCESS:

The initial research findings directed further research to investigate the mental and physical implications that Meningococcal, Meningitis or Septicaemia a patient could develop. In addition, the sequence of symptom development, diagnosis and hospital admission has a significant impact in the recovery and rehabilitation. The second phase of research comprised of determining what could be designed to fit into this specific context.

The double diamond method was utilised to determine the Discovery, Definition, Development and Delivery of the Bounce Back Box system. The initial stage of the double diamond method looked at the potential areas and products that could be improved or potentially designed to address the Acquired Brain Injuries. Research revealed that ABIs can have a broad range of issues that aren't consistent for multiple patients so a "one size fits all" was not possible. This resulted in a process that would not allow for an in-depth solution for all ABI issues.

A refined focused approach was required to be established. In determining the focus area, a more in-depth sequence of events was determined from a patient point of view. This included the initial symptoms presented for the patient to require medical assistance and admission into hospital through to the initial recovery and rehabilitation stage and progressing through to the independent recovery and rehabilitation stage.

The research report showed that the lack of information and early detection of potential issues was a major factor for the patient and carers. Interaction with patients through surveys and interviews showed the lack of knowledge on a topic that has a vast impact of their life. One survey response stated that they, as a patient in 1997, had only received one A4

piece of paper with information that wasn't relevant to continue their recovery and rehabilitation process. Additional responses from more recent patients claimed the same situation. With this theme immersing it was clear that the need for information was greater than a physical product that may not be required in the recovery and rehabilitation processes.

The hospital environment allows the opportunity for information to be shared from the very beginning for all patients and carers going through the recovery and rehabilitation process to have access. The final concept of the two part system was selected six weeks into the second semester which provided ample time to hone and redefine the current Bounce Back System.

## FINAL DESIGN DISCUSSION: BOUNCE BACK BOX REASONING:

The contents of the Bounce Back Box have been carefully considered to be both enjoyable and functional. The carer can participate and observe behaviour that can be reported to medical staff to determine if additional allied health professionals will need to become part of the rehabilitation and recovery process.

The Bounce Back Box contains the following objects;

- Stationary:  
The following stationary has been included for the patient or carers convenience as these virus' can strike at any time and any place hence you will not be prepared for this situation.
  - o **Biros** – to record notes when talking to medical staff and filling in forms
  - o **White Out** – to correct any mistakes
  - o **Highlighter** – to highlight key notes in information

- o **Coloured Pencils** – for colouring-in activities
- o **Sharpener** – to sharpen pencils
- o **Paper Clips** – to keep like material together
- o **Bulldog Clips** – to keep larger material together
- **A5 Calendar Year Diary:** Keep up to date on all appointments.
- **A5 Hardcover Notebook:** Notetaking when talking to medical staff and rehabilitation tool—sketching & writing.
- **Foam Slips:** Can be used to thicken pens and pencils or to widen the handle of eating utensils.
- **Playing Cards:** Can be used to play games – solitaire, go fish and memory
- **A6 Picture Cards:** Can be used to play memory and word finding activities
- **Uno:** Engaging rule following, communication and hand eye co-ordination
- **Guess Who?:** Engages word finding, describing features, communication and rule following
- **Colouring In Book:** Used to engage fine hand movement, improve concentration and used to reduce stress

These games or activities can be utilised in hospital with visitors such as children, siblings, parents or friends.



FIGURE 7.3 BOUNCE BACK BOX

**COLOUR:**

The colour choice of the product plays a major role to how a patient, parent, partner or guardian will feel. As the project is focused around a patient's recovery and rehabilitation while providing information in a way that would not overwhelm the recipient. As hospital rooms could be overwhelming with machines and later 'get well' and 'well wishes' gifts such as bunches of flowers the colour needed to be subdued to not overwhelm the senses.

The colour pallet chosen for the initial launch included white, black and slight colour with the branding, pink and purple. The white was chosen as a neutral colour. White symbolises clarity and freshness, it is an accurate colour to surround yourself with in times of stress it promotes clarity of thoughts (Pangin, 2017). The pink and purple promote tranquillity, peace, strength and wisdom (Pangin, 2017). These colours give the product a high quality finish and a comforting feel through the choice of materials used.

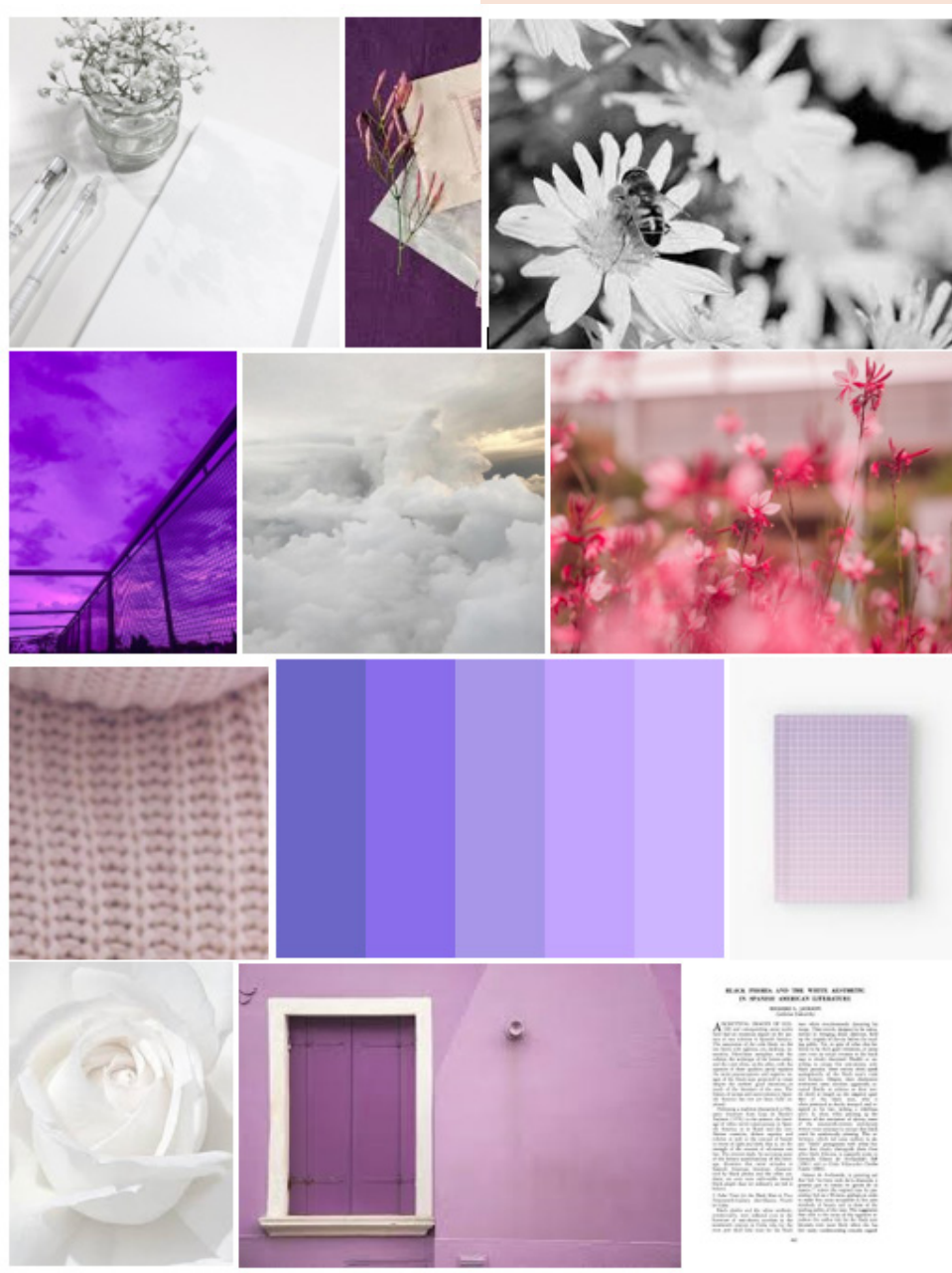


FIGURE 7.4 COLOUR MOODBOARD

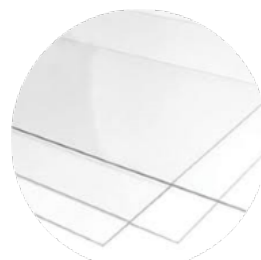
### MATERIALS:

The product is fabricated with a series of different materials to simplify the sterilisation of the product. The materials that are utilised in this design are:-

- Acrylic
- Vinyl
- Cardboard / paper
- ABS plastic
- Nylon and
- Cotton

The choice of Acrylic, Vinyl and ABS Plastic was selected because the material's surface is non-porous while being durable. This enables the surface to be sanitised frequently and to be able to take wear and tear. This is important as in a hospital setting all surfaces must be kept clean as the patient has a reduced immune system. Materials were selected for strength and durability to be able to travel with either the patient, parent, partner or guardian for ongoing medical treatments.

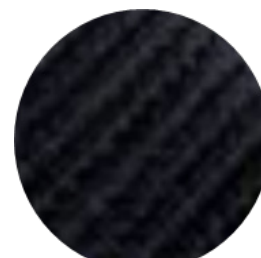
The cardboard / paper used in the construction of the lid was enclosed in vinyl to enable easy sanitisation. This reduced the overall weight of the product. Cotton and Nylon was chosen because the materials are durable but also relatively soft. These materials can be disinfected by washing the materials in hot soapy water.



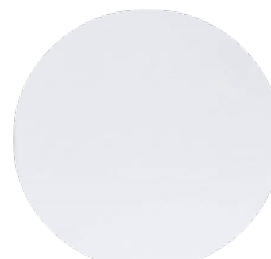
ACRYLIC



CARDBOARD / PAPER



NYLON



VINYL



ABS PLASTIC

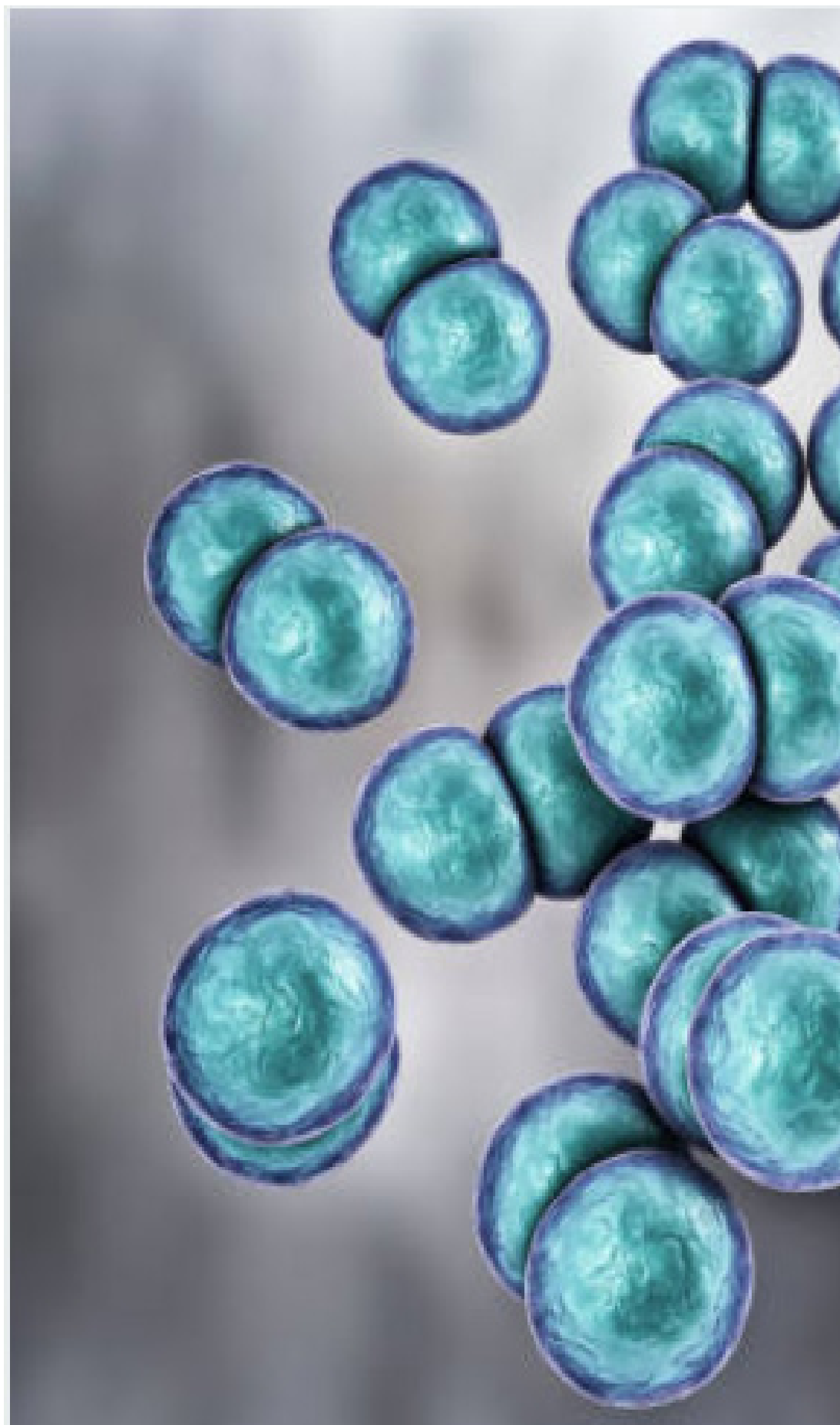


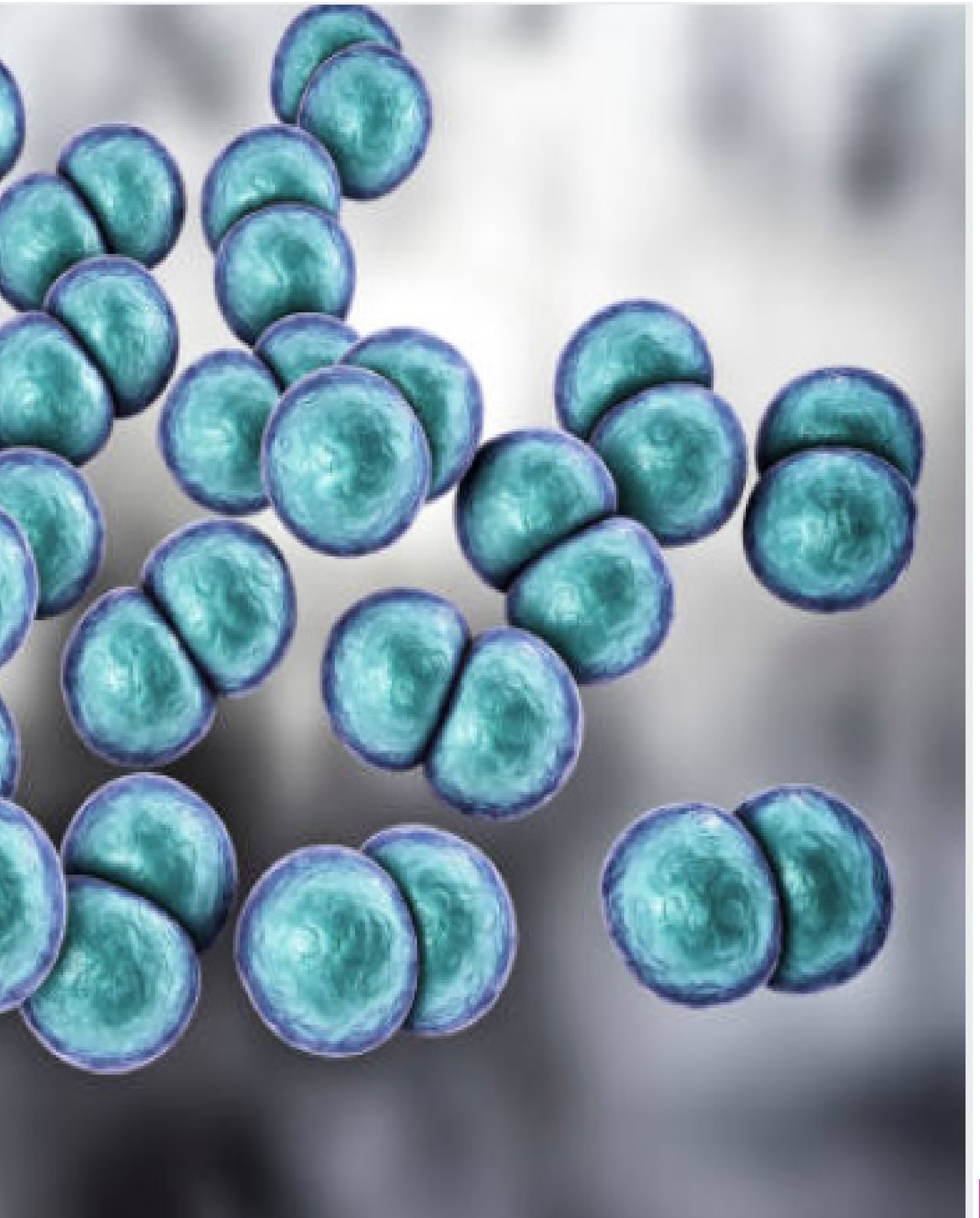
COTTON

## **SUMMARY:**

Throughout a year of researching the physical recovery and rehabilitation of a patient after acquiring a brain injury from Meningococcal, Meningitis or Septicaemia, this report concludes with the design of the Bounce Back System. Currently hospitals have a system that isn't sufficient for those who find themselves in this situation. Therefore, the Bounce Back system was designed. The Bounce Back system is a game changer which bridges the gap in the distribution of up to date and relevant medical information while connecting and promoting social interactions. Which instates Hope while offering a helping hand.

# 08 CONCLUSION





To improve a patient's physical recovery and rehabilitation experience after contracting Meningococcal, Meningitis and/or Septicaemia requires a deep understanding of physical and mental tolls of the human body as any injury from these diseases can result in physical and mental difficulties. It is important that the patient has current, correct and relevant information to proceed with their physical recovery and rehabilitation independently even if this means resulting to at-home methods.

Despite all the information that is available about these diseases there is limited knowledge readily available for the Patient's, Parents, Partner or Guardians. The limited resources were made apparent when responses from the survey were collected. One survivor which was diagnosed with these diseases in 1997 had received limited information on how to proceed with their physical recovery and rehabilitation. This is the same experience as another survivor who was diagnosed two years ago.

The recovery and rehabilitation process are not the same with each patient. Depending on the length of hospital stay, the bodies reaction to the disease and the outpatient struggle whether physically or mentally, are all different. Some patients may experience similar symptoms to one another but the body and brains ability to adapt differs because of the age and experience of the patient. Mental and physical health need to have the opportunity to recover and rehabilitate.

The opportunities that have made themselves apparent throughout the literature review, survey and interview stages, is the limited information and resources the patient have available to them. It is easier to recognise and improve the physical restrictions than it is recognise mental limitations. As physical issues are readily apparent, mental restrictions have to be identified with specific tests.

These findings have shown that three areas a product, system or service can be implemented to better the physical recovery and rehabilitation process from Meningococcal, Meningitis and/or Septicaemia. These areas can also improve the recovery and rehabilitation of an acquired brain injury. These areas are;

1. Patient Orientated, Primary User
2. Parent, Partner or Guardian Orientated, Secondary User
3. Community Orientated.

The design opportunities which are laid out in the report are;

- Information and Community Application
- Activity or Care Box
- Initial Communication Application

The design limitations or considerations for these design opportunities are;

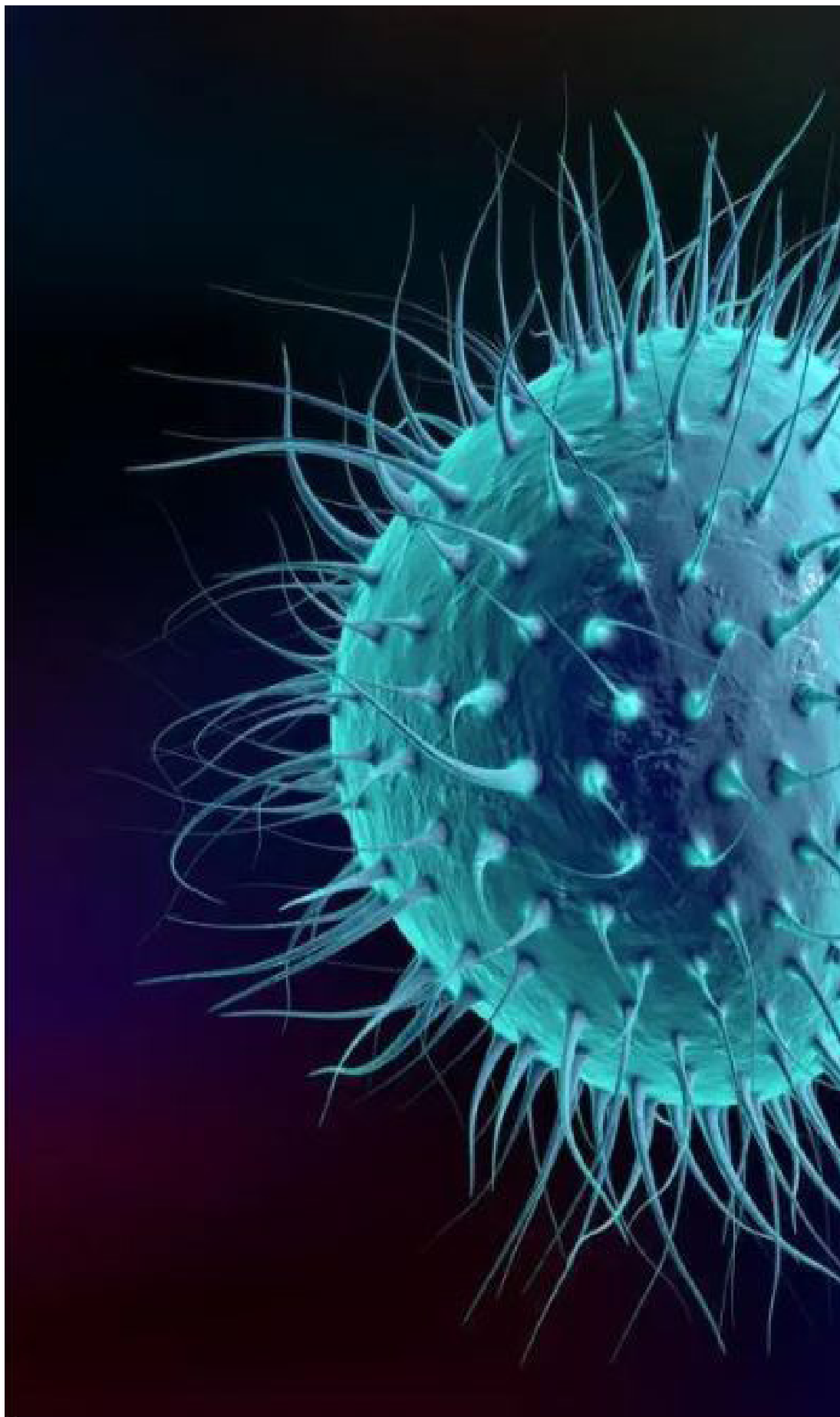
- The user may not have the technology of a compatible phone or tablet readily available
- The solution must not be gender specific
- The solution needs to be able to be adjusted to the level of ease the user requires
- It needs to be able to be adjusted to the vast range of the patient's recovery and acquired brain injury status.

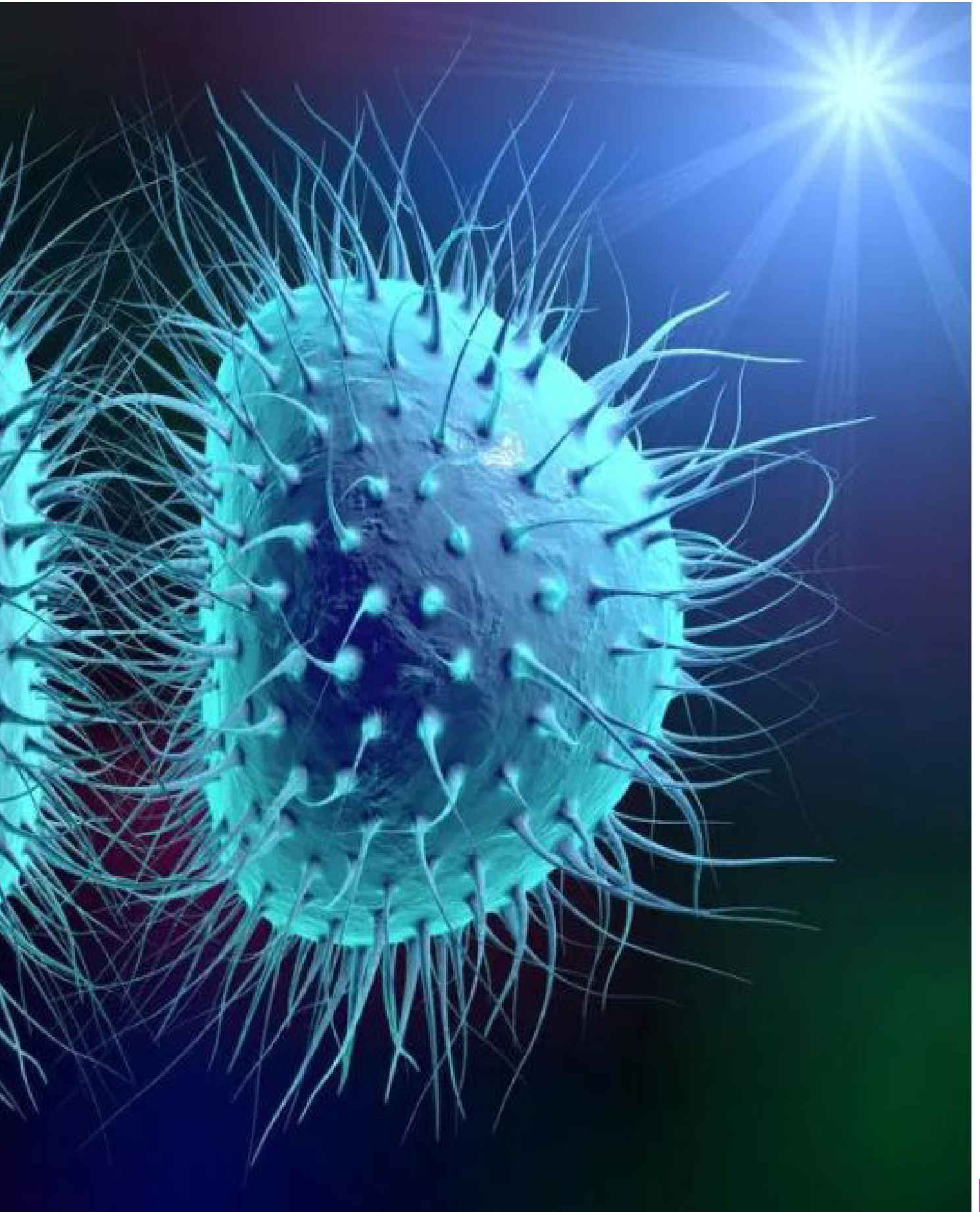
As discussed, relevant information is available to sufferers of Meningococcal, Meningitis and Septicaemia and those who have developed an ABI through various scenarios. This dissertation is highlighting the real-world stories to the theory and primary objective of bridging the gap between patient and information. Together the Opportunities have highlighted the gaps that are currently present. Through development of the opportunities, with input / feedback from



professionals in the medical industry, can become a tool for patients throughout Australia who are currently or will recover in the future.

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# 10 APPENDIX





**APPENDIX A - Patient Experience:**

Below is an example of a Patients Experience of the virus Meningococcal, Meningitis and Septicaemia;

Day	Symptoms	Blood tests
1	<b>Initial Symptoms Present</b> Nausea and fatigue	
2	<b>Symptoms Progress</b> Nausea, Lethargic and Headache	
3	<b>Symptoms Progress to Hospital Admission</b> Vomiting, headache, temperature, weakened body (limited control) Tried movement - resulted in fainting, black eyesight and legs giving out Emergency Services were contacted 5 minute assessment to stabilise Patient to Admit into Emergency at Hospital  3hrs later - Moved to Resuscitation Unit of Emergency 2hrs later - Moved into ICU isolation with suspected Meningococcal	<b>BLOOD CULTURE MICROBIOLOGY #1</b> Collected - DAY 3 @ 13:00 Registered - DAY 3 @ 13:35 Specimen - Blood Growth After - 10.7 Hrs Culture - Neisseria Meningitidis  <b>BLOOD CULTURE MICROBIOLOGY #2</b> Collected - DAY 3 @ 13:00 Registered - DAY 3 @ 13:27 Specimen - Blood Growth After - 15.6 Hrs Culture - Neisseria Meningitidis
4	10hrs later - Patients kidneys are failing resulting in kidney dialysis 2 hrs later - Patient is induced into a coma on ventilation  Diagnosed with Septicaemia, Toxic Shock, Meningococcal and suspected Meningitis	
5	Microbiology Laboratory Tests Time for Diagnosis - 48Hrs	<b>NEISSERIA MENINGITIDIS REFERENCE LABORATORY</b> Collected - DAY 3 @ 20:05 Registered - DAY 3 @ 20:25 Specimen - Blood Date Received - DAY 5 Organisms Identified - Neisseria Meningitidis Serogroup - B
6	Started the 48hr process of the Patients coma being suspended	
9	Patient can breathe by themselves Ventilator and tube are removed	

Day	Symptoms	Blood tests
10	<p><b>Ward Change ICU to Infectious Diseases</b></p> <p>Patient is well enough to control their breathing, can swallow resulting in soft food and drink</p>	
17	<p><b>Inpatient Physiotherapy Discharge Summary</b></p> <p>Inpatient physio completed with at a level which allows patient to walk with 2x Canadian crutches, Stairs x3 with rail and crutch, Fatigues Rapidly, and Tight Calves</p>	
19	<p><b>Patient is well enough to continue Recovery at home</b></p> <p>Can perform basic human needs                      Feed them self, walk small distances, go up and down stairs, shower while seated by them self and go to the toilet.</p>	

## APPENDIX B - Caleb Thorburn Age 2:

Caleb Thorburn (affectionately known as Cal) was born on the 7th of October 2000, our first born child and now brother to Gemyah and Sweeney.

From that day forward Caleb set the pace, boundless in his appreciation for life with stamina to match. Every moment with Cal was fulfilling, abundant, spirited, captivating and well lived. Cal was a happy, confident and cheeky little boy with a fondness for music, all things outdoor, boyish adventure, dancing, ball sports and assisting around the house, readily equipped with a broom, mop, hammer or wheelbarrow to manoeuvre.



Cal was a tall, strong and charming looking little boy. Smiling and laughing wasn't just his response to entertainment it was his gift. With great big blue sparkling eyes, a hint of mischief and spirited twinkle, Cal had a vitality that was so endearing. His persona was beyond his years and more beautiful than his shell was his soul. Laughing, hugging, kissing, excitement, roughing it up, sharing, racing to the front door to greet our visitors, listening for Daddy's truck, running up and down the verandah.....we saw our boy embrace life with awesome enthusiasm. With a joyful radiance Cal was at his happiest in the company of others. Greater than any material pleasure was his love of people especially his large family network. He relished the attention, loved a gathering and intensified a surge of emotions within you in the pleasure of his company.

Caleb was a unique and special child. His story deserves to be retold not because of the tragedy of his death but because of the powerful, meaningful, happy and heart-warming commitment Cal had to living. Subsequently the memories he has left with so many people are indelible and that is why Cal's life is enduring. His impact on others was astounding.

Caleb's energy was also very tender. He was affectionate, adoring and playful. Time was never wasted with an admirable determination to be part of everything. It is hard to believe that such a beautiful young child with a world of promise was robbed of the continuity of life. His passion for the blessing of every moment he lived is the reason we feel committed to establishing his foundation. Caleb epitomised the pinnacle of life and that is what drives us in our endeavors to protect and preserve the greatest and most precious of all gifts....our lives.

Caleb, alongside his siblings, is the essence of our hearts. He inspired us with his zest and the totality with which he lived and now empowers us to make a difference in the fight against meningococcal disease, to ensure the dreams and pursuits of every life, be it young or old is realised. Truly an honour, a privilege, a blessing to love you Caleb

Thank you cherished son for you..... ours to treasure, adored forever.

The 17 hours that unfolded between Friday the 5th and Saturday the 6th of April in 2002 will no doubt be some of the most profound measurements of time in our lives. It is incomprehensible to understand the intimacy of our journey and the experience of meningococcal disease that claimed the life of our precious son Caleb. The script is too raw to be exposed in its entirety and the reality is that the characters are not fictional. We are an everyday loving family that have been utterly devastated by a disease reminiscent of something from the dark ages.

We had enjoyed a normal morning of activities with our son Cal. An unusually early afternoon sleep preceded the onset of symptoms that marked the beginning of the tragic events that were to unfold. Without warning our Son went from effervescent to debilitated within hours. As he was a healthy and energetic child his decline was most obvious and frighteningly rapid. Whilst we were unaware that our child was suffering from meningococcal disease we were very distressed by his presentation and had rung for medical assistance. We were advised to visit a surgery later that day.

Caleb's condition continued with no improvement even after the administering of Panadol and Nurofen. His temperature was spiking at 41, he was motionless, twitching and the appearances of purple pinprick spots were on his arm, neck and torso.

After receiving a diagnosis of viral infection we returned home from the doctor's surgery, confused but relieved, to care for our son. Many conversations with family and friends had taken place that afternoon, all pertaining to the welfare of Caleb and to withdraw our inclusion from a big weekend of activities to allow Cal to get better.

Later that evening our worry continued to intensify as Caleb was unable to support his weight and was deteriorating. He had vomited and was not engaging with any stimulation. We did not leave his side especially as he was mildly convulsing. Every 15 minutes we would turn him from his lying position of stomach to his back. It was at this point that we were horrified to see the expansion of his spots into a birthmark rash. A deep purple mark extending across his chest had appeared within minutes.

Caleb was rushed to Box Hill Hospital where he was placed in intensive care and treated with urgency. The rash continued to spread and whilst medical staff were communicating their intentions, reassurance of his wellbeing was not forthcoming.

We began to become aware that Caleb's life was desperately fragile.

In the early hours of Saturday morning it was required Caleb be induced into a coma to stabilize him for transfer to the Royal Children's Hospital and to alleviate his pain. Caleb looked at us with pure love before the affect of the coma took hold. It is an image that will last with us forever. It reflected the spirit of our son and promoted the love that forged the bonds between parents and their children. For those brief moments the connection between us overshadowed the environment we were in and the plight that was in front of us.

Upon transfer to The Royal Children's Hospital the medical staff continued to exhaust every possible intervention for our son Caleb. So much unfolded in those hours. The praying, the pacing, the emotions....hope, shock, disbelief... And then the emergence of the doctors with the resigning removal of their theatre hats to deliver the tragic news. Caleb's organs were failing and that nothing more could be done.

Traumatised beyond recognition we sang to our son, we kissed him, we held him, and we loved him into eternal life. With a single gentle tear that rolled down his beautiful face Caleb farewelled us. At 9.05am on Saturday the 6th of April our son became an angel.

His death from meningococcal strain B was so cruel, so utterly devastating that we will never recover from witnessing the pain our cherished son endured and the subsequent grief we will live with forever.



## APPENDIX C - Troy Pocock Age 22:

Troy contracted the disease while on a working holiday in London with his girlfriend. The Pocock family lives were turned upside down when they received a phone call from the Chelsea Hospital in London warning them that Troy was in critical condition after contracting the Meningococcal disease.



Troy started to feel ill the morning of December 29th 2001 and he thought he was just getting the flu.

It wasn't until he was so sick vomiting, diarrhoea, high temperature, joint stiffness and the appearance of blotches on his eye lids that Meg realised it was something more serious than the flu, she rushed him to the hospital which was ten minutes away.

Troy was vomiting blood by the time he got to hospital and his condition was critical. There wasn't much the hospital staff could do, he was placed on life support and administered antibiotics but was to pass away within hours.

Troy's brother Scott and Meg's mother flew to London to bring Troy home but didn't learn of Troy's death until they were in Tokyo half way to London. They dealt with the cremation and the packing of Troy and Meg's belongings.

Scott brought Troy's ashes home in his backpack which sat next to him and Meg all the way home. Troy and Meg had left on the 7th of October 2001 to venture the world but Troy died on December 29th. On the 9th of January 2002 Meg came home without the love of her life.

A memorial service was held on the 12th January 2002 and his ashes were scattered over the Shoalhaven River.

On the 14th December 2003 which would have been Troy's 23rd Birthday his friends organised and dedicated a memorial bench at Bangalee Reserve. The reserve overlooks his beloved Shoalhaven River from where his ashes were spread. Many friends have spent a quiet moment in reflection sitting on Troy's bench and the words inscribed have been an inspiration to many.

The inscription reads "Make each day a magnificent adventure".

Troy and Meg each went to a different doctor before they left but neither of them were advised to have immunisation against Meningococcal even though the incidence of this disease in London is even higher than Australia.

An immunisation needle would have cost \$70.00 which would protect against the C strain, if only Meg and Troy had been told this our Troy would still be here with us now.

### APPENDIX D - Survey Questions:

Physical Recovery and Rehabilitation from a Brain Injury - Meningococcal, Meningitis & Septicaemia  
This project is being undertaken as part of an Honours study at Queensland University of Technology. The purpose of this project is to develop recognition of acquired brain injuries and the importance of subsequent physical recovery and rehabilitation of adults preferably aged 18 to 25 years but others are welcome, resulting from Meningococcal, Meningitis and Septicaemia.

You are invited to participate in this project because you are between the preferably ages of 18 to 25 years, others are welcome, or a guardian who has experience in the Physical Recovery and Rehabilitation from a Brain Injury after suffering from Meningococcal, Meningitis and/or Septicaemia. The purpose of this project is to develop recognition of acquired brain injuries and the importance of subsequent physical recovery and rehabilitation of adults aged 18 to 25 years, resulting from Meningococcal, Meningitis and Septicaemia.

1. What age did you contract either diseases? (Meningococcal, Meningitis or Septicaemia)
  - 18 - 19
  - 20 - 21
  - 22 - 23
  - 24 - 25
  - Other...
2. What is your Occupation?
3. What disease did you contract?
  - Meningococcal
  - Meningitis
  - Septicaemia
  - Other...
4. How long was your hospital stay?
5. How severe was your reaction to the diseases?
  - Tissue damage
  - Organ failure/transplant
  - Amputation
  - Communication issues e.g. broken speech
  - Hearing troubles
  - Other...
6. When released did you receive any information about recovery and rehabilitation?
  - Yes
  - No

7. What information was this?  
Clinical Psychologists  
Orthoptist (vision)  
Occupation Therapist  
Speech Pathologist  
Physiotherapist  
Orientation and Mobility Specialist  
Other...
8. Was this information helpful?  
Yes  
No
9. Who provided this information?
10. Whilst in hospital what physical recovery therapy were you provided? e.g. Physiotherapy
11. After release from hospital what physical recovery did you continue?
12. What did you struggle with most once released from hospital?
13. What was your physical rehabilitation process?
14. What information would you have liked to receive upon your release from hospital?
15. What would have been most helpful in your recovery and rehabilitation process?
16. Was there any piece of equipment that aided in your physical recovery and rehabilitation process?
17. Are you willing to participate further by taking part in an interview?  
Yes  
No

### APPENDIX E - Interview Questions:

Please answer the following questions in as much detail that you can:

1. How many years into recovery are you? How many years since you were diagnosed?
2. What was the physical toll on your body? What is the journey to adapt to tissue damage or amputation?
3. How was your experience when first learning that you had communication issues?
4. What did you mean with 'get back to normal'?
5. Was there activities or methods which helped you achieve day to day activities?
6. What activities or scenarios did you undertake to regain the ability to walk, balance and your strength?
7. How did you continue your physical recovery away from the gym in a home environment?
8. What exercises did you use in this recovery?
9. How did you manage your fatigue? What tip or tricks where you told or discover during your recovery?
10. How big of a role did mental health play in your recovery?
11. What would you tell anyone who has been diagnosed with Meningococcal, Meningitis or Septicaemia?
12. Is there anything else you would like to share with me?

Please answer the following questions in as much detail that you can:

1. How many years into recovery are you? How many years since you were diagnosed?
2. How was your experience when first learning that you had communication issues?
3. What difficulties did you have with your fine motor functions?
4. How did you adapt with short term memory issues?
5. Was there activities or methods which helped you achieve day to day activities?
6. How did you improve your reading and writing comprehension?
7. How did you continue your physical recovery as an outpatient?
8. What exercises did you use in this recovery?
9. How did you manage your fatigue? What tip or tricks where you told or discover during your recovery?
10. What processes where used when you were relearning to walk? (e.g. walker on flat to crutches on flat to crutches on incline....)
11. Is there anything else you would like to share with me?

## APPENDIX F - Interview Sample Coding:

Please answer the following questions in as much detail that you can:

### 1. How many years into recovery are you? How many years since you were diagnosed?

I had Men B and septicaemia in Aug 2013 so coming up to 7 years since my event

### 2. What was the physical toll on your body? What is the journey to adapt to tissue damage or amputation?

greatest foot length must be preserved.  
Dead tissue

I had a bi lateral forefoot amputation ( from half of each foot removed ) , tip of a finger removed, my heel were necrotic so these had to be removed, then having muscles removed from my thigh, layered up on my heel and covered in skin grafts. Along with this was multiple wounds, a few in my arm that were quite deep and took some months to heal.

Blisters/Dead tissue?

Adapting to the tissue damage even 7 years on was a long road, after surgery I want able to weight bear for 6 weeks and looking back the affected areas were very red angry looking and uncomfortable. Over time my feet have healed very well. My heel are like jelly and a bit weird but they do the job ( look like a loose jumper LOL ) and are soft and spongy. Something I don't touch that often as a feel weirded out by it.

Not independent

Pain/Sensation improved slightly

Pain I suffer over the years from the surgery on my feet has somewhat subsided over the years, I used to have pins and needles from my knee down but now its proolly from my ankle down only. My feet burn all the time I'm on them and the most "normal" part of my day is when I wake up, no tingling, no pain. I just feel normal. The pain has settled over the years and is something I have learnt to block out I guess as this is the new normal.

live in constant pain

muscle loss/control issues

Additional physical toll on my body was the initial physical strength. I couldn't lift a kilo. I had the shakes. I couldn't hold a knife and fork. I think this was more from being in ICU in an induced coma, the surgery, and all the drugs I was on to keep me going. I also had kidney and liver failure so yeah was given a lot to deal with in a short span of time.. Rehab daily whilst in hospital (total of 108 days in hospital ) gave me the time to get a lot of physical strength back and get myself into a reasonable working and walking order. I was able to return to full time work almost 6 months to the day from when I became sick. I was on crutches but wanted to return to a normal as possible life and this helped me with my mental rehab.

Motor Control

Physical Recovery.

Normality/Independence + Equipment.

I now work 50 – 55 hours a week so yeah I've made a pretty reasonable recovery!

### 3. How was your experience when first learning that you had communication issues?

I did have communication issues only whilst in hospital and to be honest I was so drugged up that I didn't really know it was an issue. I feel now that my brain isn't as sharp as it used to be, that could be age though. I still have a great long term memory. My eyesight used to be perfect and I don't know again if it has degraded from age or what I went through

Residual Affects.

### 4. What did you mean with 'get back to normal'?

Independence Routine - to Believe illness.

Normal being going back to work, which I spend too much time on, spending time shopping with my wife, going out for dinner, out on the weekends, just any normal activity that I did before I had the amputations etc. I has a wheel chair when I initially got out of hospital which didn't feel normal and

Didn't know how to feel.  
↳ wanted to walk - Independence.

Please answer the following questions in as much detail that you can:

1. How many years into recovery are you? How many years since you were diagnosed?

A. I was diagnosed on August 25, 2018 2 years into recovery.

2. How was your experience when first learning that you had communication issues?

Communication  
mental  
difficulties

A. It was very difficult to come to terms with. I have a few issues which I'll outline for you

below. A lot of these issues were huge for the first few weeks. I've learnt to be quiet, calm

learnt to  
Adapt.

and to speak with meaning and purpose to avoid having to repeat myself as well as avoid

Appear as  
"Normal"

speaking when I'm not required to. Through working with my speech therapist, I was able

Effects Reduced  
but still recognised.

to reduce the effects greatly, but they're still present. My mother often says that someone

who has never met me before would never notice, and that I would just appear as someone

who speaks slowly. She does notice, because she knew me before the incident.

Problem with  
word finding

a. Word synthesis: To this day, I have an issue with synthesising the word in my head

and getting it out. So, a lot of the time I will have to navigate my speech around the

word I cannot remember. Alternatively, my speech therapist taught me a way to

push through it, and that is to describe the word. Describe the definition, what it

Technique  
to find word

does and what it relates to and that usually helps me find the correct words for what

I am wanting to say.

Stuttering/Tipping  
over sounds

b. Stutter: I have trouble stuttering with certain words, I often describe it as "Tripping

Over" some words. Its most common in words where one sound in the word has a

very similar mouth shape to form it as the next sound. Its hard to explain, but the

stutter was a huge adjustment as well.

Problem with  
emotions with  
speech.

c. Trouble speaking when rushed: This one is an important one for me because it has

probably affected me the most. If I ever feel an immense sense of pressure, or the

person I am speaking to seems to be really rushing for me to get out my words, I will

not be able to get them out. Its hard to explain but I often use a car crash in my

brain as an analogy, its like if my brain is a one way street, and I try to rush words

out, there is a big car crash and I have the words / the sentence in my head but I

can't push it down the "street" and vocalise them. Its strange and easily the most

frustrating.

Easiest way  
to describe  
problem

Physical toll  
which leads to  
mental.

d. Forming words: This is different to the stutter or word synthesis, in that it's like my

mouth will get lazy and trail off on the end of some words. I've noticed it's most

common when I am trying to express an opinion in a rushed way or I'm speaking for

a long time. It also happens when I have to repeat myself and I find the words hard

to pronounce. The end of words will just sometimes trail off.

e. Word Difficulty: Some words are just plain harder to pronounce. The words that are

more difficult to pronounce are not necessarily bigger or more complicated, its often

to do with how the words are formed by the mouth, its like I lost some word forming

dexterity somehow.

Complicated  
mouth  
movement

f. All of these speech difficulties worsen when I'm tired, drunk or other inebriated. I

don't often drink because my neurologist did advise against it for the first few

months of recovery but I just continued with trying not too because it wouldn't be

that good for me.

APPENDIX G - Full data File:

Timestamp	Email Address	What age did you contract either diseases? (Meningococcal, Meningitis or Septicaemia)	What is your Occupation?	What disease did you contract?	How long was your hospital stay?	How severe was your reaction to the diseases?
5/21/2020 18:50:19	danh7270@gmail.com	20 - 21	Student Software Engineer	Sinus Infection that formed an abscess	5 weeks	Communication issues e.g. broken speech, Fine motor function issues, short term memory issues, reading and writing comprehension as well as focus retention issues.
5/25/2020 20:31:47	aries_engel7@hotmail.com	15	Communications assistant	Septicaemia	1 week	Brain injury, cognitive, memory
5/25/2020 21:39:17	yaz.meirish37@hotmail.com	18 - 19	Hospitality	Meningococcal, Meningitis	1 week	no known reactions beside blood loss
5/25/2020 22:06:02	paulg@keenoffice.com.au	37	Group General Manager	Meningococcal, Septicaemia	15 weeks	Tissue damage, Organ failure/transplant, Amputation, Communication issues e.g. broken speech, Speech issues were only present during ICU and when on hospital drugs
5/25/2020 22:17:32	courtney.mackay2@griffithuni.edu.au	24 - 25	Trade support worker	Meningococcal, Meningitis, Septicaemia	2 weeks	Communication issues e.g. broken speech, Memory loss
5/25/2020 23:32:51	williams_jeanne@hotmail.com	28	Security Ranger	Meningococcal, Meningitis, Septicaemia	5 weeks	Organ failure/transplant, Communication issues e.g. broken speech, Brain Damage
5/26/2020 7:38:45	linda.gumley@yahoo.com	11 or 12	Administration	Meningitis	13-17 weeks	Bed ridden, severe headaches, could not stomach food for 5ish months.
5/26/2020 8:17:52	pony3032@gmail.com	51	TAFE Teacher	Meningococcal, Meningitis	5 weeks	Septic arthritis, short term memory loss
5/26/2020 19:14:19	tarleap12@gmail.com	18 - 19	Student	Septicaemia	13 weeks	Tissue damage, Organ failure/transplant, Communication issues e.g. broken speech, Hearing troubles
5/28/2020 11:36:49	payney08@hotmail.com	18 - 19	Plant Maintenance Supervisor	Meningococcal, Meningitis	3 weeks	Tissue damage, Memory loss, unexplained pain in lower limbs
6/01/2020 3:44	wedgeben@yahoo.com	22 - 23	unemployed	Meningococcal	2 weeks	Tissue damage
6/04/2020 6:33	13pike12@gmail.com	4	none	Meningitis	28-52 weeks	Communication issues e.g. broken speech
6/04/2020 7:56	oz_us@hotmail.com	1 - 2	Designer	Meningitis	5 weeks	Very short temper

When released did you receive any information about recovery and rehabilitation?	What information was this?	Was this information helpful?	Who provided this information?	Whilst in hospital what physical recovery therapy were you provided? e.g. Physiotherapy
Yes	Occupation Therapist, Speech Pathologist	Yes	Royal Brisbane and Women's Hospital	Some slight physiotherapy. Not much though. I think they thought I was a bit too fragile to do much more because of the fine motor issues.
No	None	No	N/A	None
No	None	No	N/A	None
Yes	Occupation Therapist, Physiotherapist, Orientation and Mobility Specialist	Yes	SA Health and OP&SA provided and delivered me these services	Physio on a dialy basis to learn to walk , gain balance and strengthen muscles, undertook gym/rehab each day when i was able to , approx 6 - 8 weeks after my amputation surgery.
Yes	Clinical Psychologists	No	Nurse	None
No	None	No	N/A	None
No	None	No	N/A	None. Only doctor and nurses with routine checks
Yes	Physiotherapist, Neuropsychologist	Yes	Physiotherapist	Given a walking stick!
No	None	No	N/A	None
No	None	No	N/A	None
Yes	Orthoptist (vision), Physiotherapist	Yes	n/a	Physiotherapy
No	Clinical Psychologists	No	doctor i think	physiotherapy
Yes	Behavioral tips, my parents were told i would have certain problems which will be temporary	Yes	The doctor i believe	None



After release from hospital what physical recovery did you continue?	What did you struggle with most once released from hospital?	What was your physical rehabilitation process?	What information would you have liked to receive upon your release from hospital?
It was mostly fine motor control exercises, writing, typing. That sort of thing.	Exhaustion and coming to terms with living with a brain injury. Life is much harder now. The biggest thing is always being tired. And not having the confidence in myself to do certain things.	Walking, typing speed tests mostly.	More information about how hard it would be. Maybe direction to a support line/group where I could find more info. I've since stopped physical and speech therapy, but I would love to go back now that I've recommended uni and work, because I've found so many other issues that we didn't address
None	My memory, attention, understanding simple things	I didn't have one	Support in understanding how my brain changed
None	Strengthening my muscles and energy	none.	information on how severe my case had been and how to ease back into normal routine
Gym rehab and physio support for approx 3 months though OPFA and the Repat hospital in Adelaide, where I was based after being released from FMC.	OT each day whilst in hospital plus gym session 7 days a week also whilst at the repat, they made an exception to me going to the gym as the gym was only monday to friday but the head of the dept said if i want 7 days a week gym that he would get someone to pick me up, get me into the gym and take me back to my room, really helped me. The physical strength gains gave me the mental strength to push on and on to get better and get back to "normal"		A plan for a 8 - 12 week period at a time.
Psychological	Memory loss, speech, physically weak (collapsed on the floor 1 day out of hospital)	Very little information from doctors, little follow up, only 1 session 2 years later to test my memory	Expectations- for example I'd never had serious mental health issues prior to my disease yet in the 12 months following I was hospitalised for serious mental health conditions. Long term (5year) follow up would have been nice, scans ect. I could never complete my University course and I still struggle with memory and processing skills (7 years on)
None because I got sick overseas on holidays Being young it was hard to be a kid again, always exhausted. Took a year before I was able to spend a whole day at school.	Memory loss, speech, physically weak, writing, walking	I just had to learn everything myself	Help with memory tricks and speech
physiotherapy eventually when able to walk again	Learning, physical activity extreme fatigue	None	No, parents were given information in hospital, but no follow up appointments or recommendations given. This was back in 1997
None	Movement - the septic arthritis affected every joint in my body, particularly the knees.	At home exercising with rubber bands and against the wall squats. Supplemented by several visits for physio at the hospital.	Something more than the neuropsychologist wanting to take my drivers licence away!
Healing at home further 3 weeks off work	Hearing and walking	Learning to walk again Rest for a few months then back into Rugby League training	N/a
yes	Fatigue	none	Side affects, long term issues
began speech recovery	sleep	none	none
None	speaking and reading	Mainly tubers as physically i was okay	"He will have speech difficulties for a couple of years so i suggest getting a tutor or special lessons with a teacher"
	Anger	None as far as i remember	I was a baby

What would have been most helpful in your recovery and rehabilitation process?	Was there any piece of equipment that aided in your physical recovery and rehabilitation process?	Are you willing to participate further by taking part in an interview?
Just a support person there to talk to, someone with knowledge in the recovery process. I encountered questions that I had to answer myself and it was very scary because I didn't know what to expect.	I didn't use any equipment.	Yes
A counsellor	No	Yes
Knowing what I was able to do and unable to do as a result of lack of energy and strength	No	No
As above	General gym equipment was helpful, just to build myself up from where I was, which was very weak and no strength	Yes
Clarity, information, kept in hospital longer	No	Yes
Help getting a job with a brain injury for someone with memory loss.	Any game to keep my mind active and especially my calendar in my phone to remember everything	Yes
More Checks. They mainly went by what we told them instead of actually development checkups post sickness.	No.	No
I cannot suggest anything in my case.	Walking stick - needed for the septic arthritis. It was about twelve months before I retained full mobility.	Yes
N/a	No	No
More education on the disease and the after affects	No	Yes
none	none	Yes
more information and confident symptoms of meningitis	n/a	No
I was a baby	I was a baby	Yes



**PHYSICAL RECOVERY AND REHABILITATION FROM A BRAIN INJURY -  
MENINGOCOCCAL, MENINGITIS & SEPTICAEMIA  
BACHELOR DISSERTATION**

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