

**Lost in translation: towards a standard hospital
health passport for people with Intellectual
Disability, an exploration of minimum data sets**

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For Ronaliza

Declaration

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university.

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Abstract

The health needs of people with intellectual disability (ID) are complex. People with ID are more likely to use hospital services than the general population yet there is evidence that hospital professionals lack the knowledge and experience to take care of them. The lack of knowledge and understanding of hospital professionals is one of the many obstacles faced by people with ID when accessing hospital services. Hospital health passports are increasingly being used by people with ID to overcome some of the barriers in accessing hospital services. Currently, there are different hospital health passports being used nationally and internationally.

The purpose of this study is to identify the minimum data requirements of doctors and nurses for a standard hospital health passport. Several research questions are stated to guide the study.

- Do doctors and nurses find taking care of people with ID more difficult compared to people without ID?
- Do doctors and nurses require more background information to care for people with ID?
- What are the implications of a standard hospital passport in relation to future hospital information systems for people with ID?
- Is there a difference between the information required by doctors and nurses for the hospital health passport for people with ID?

This study uses both qualitative and quantitative data to resolve the research questions and achieve the aim of identifying the minimum data requirements of doctors and nurses for a standard hospital health passport. Case scenarios using an ethnographical observation method is used to explore the challenges of hospital doctors and nurses when people with ID access the hospital. A survey questionnaire was fielded to collect the opinions of hospital doctors and nurses which are measured and allow triangulation of data.

This study explores the idea of a minimum data set for a standard hospital health passport for people with ID. The content of hospital health passports from national and international sources are analyzed to form a list of items of information presented to hospital doctors (n=8) and nurses (n=35). Overall, 42 items of information are aggregated from 6 hospital health passports. All 42 items are ranked by nurses with moderate to very high importance while doctors rank 38 items with

moderate to very high importance. The study shows a difference in opinion to some items of information, but more importantly, the study shows that both doctors and nurses find a majority of items to be similarly important. This is a step towards developing a standard hospital health passport for people with ID.

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Abbreviations

ID - Intellectual Disability

HIQA - Health Information and Quality Authority

WHO - World Health Organization

ICD - International Classification of Diseases

A&E - Accident and Emergency

CEO - Chief Executive Officer

ANP - Advanced Nurse Practitioner

GP - General Practitioner

Chapter 1 Introduction

“We, the ones who are challenged, need to be heard. To be seen not as a disability, but as a person who has and will continue to bloom. To be seen not only as a handicap, but as a well intact human being.”

-Robert M. Hensel

The right to be safe and to access much needed health services are some of the fundamental human rights that everybody should receive. Acknowledgement of these rights creates a drive to promote the provision of better healthcare for everybody, including people with intellectual disabilities (ID). UN International Covenant on Economic, Social and Cultural Rights includes the right to timely and appropriate health care, when stating that health facilities, goods and services have to be accessible to everyone without discrimination (Sixsmith et al. 2005).

The health needs of people with ID are complex. They are more likely to suffer from major illnesses and more likely to receive hospital care than the general population (MENCAP 2004). Unfortunately when people with ID enter the hospital they face significant obstacles in accessing equal treatment from health and hospital services. It is reported that people with ID get a 'worse deal' from health service than people without ID (Department of Health 2001).

Overcoming obstacles in accessing equal treatment for people with ID requires adjustments in policy and practice for service providers. One reasonable adjustment that services can adopt is the use of hospital health passports for people with ID (Blair 2011). A hospital health passport is a document that contains information, not just about health, but also other important information arising from the persons disability.

1.1 Background and context

Hospital health passports are increasingly being used by people with ID to help negotiate a better hospital experience. The use of hospital health passports have resulted in more personalized and dignified care and found to have a direct impact on treatment of people with ID (Blair 2010). The hospital health passport contains important information like current medication and health history but differs from a health summary as they also contain information such as methods of communication and the person's preferences.

There is evidence of use of hospital health passports in countries around the world such as the UK (Brodrick et al. 2011), Canada (Kaufman n.d.), New Zealand (Ministry of Health 2011), the US, Australia and other European countries (Blair 2011). In Ireland, several hospital health passports are being used. Some organizations in Ireland have adopted a UK version while others have created their own hospital health passport .

At present, information contained in the hospital health passports do not conform to any national or international standard. The hospital health passports varied in content and page length from two pages going up to eight pages. This means that information are still fragmented and may not meet the requirements of healthcare professionals in the hospital. Vital information could be lacking in the hospital health passport or saturated with unnecessary information. Without a developed coherent and integrated approach to health information, documentation is poor and information can be lost or there is an over-reliance on memory (HIQA 2013).

1.2 Aim of the study

The aim of the study is to identify the minimum data requirements of doctors and nurses for a standard hospital health passport. It explores the possibility of standardization by analyzing and comparing the items of information from available hospital health passports.

1.3 Research questions

- Do doctors and nurses find taking care of people with ID more difficult compared to people without ID?
- Do doctors and nurses require more background information to care for people with ID?
- What are the implications of a standard hospital passport in relation to future Hospital Information Systems for people with ID?
- Is there a difference between the information required by doctors and nurses for the hospital health passport for people with ID.

1.4 Overview of the research

A literature review is conducted to explain the complicated nature of intellectual disability and establish the need for a standard hospital health passport for people with ID. The implications of standards in general and a standard hospital passport in particular are also explored.

The research questions and aim are addressed primarily by a triangulation of qualitative and quantitative data. Case scenarios regarding the experiences of people with ID in hospital settings provided a platform for learning about deficits of information experienced by doctors and nurses. Opinions of doctors and nurses regarding hospital health passports were gathered through a survey questionnaire, then measured and related to the scenarios to generate the conclusions of the study.

1.5 Overview of the dissertation

This chapter presents the motivation for the research, the research questions and aim and an overview of the research.

Chapter 2 presents the literature review. It explains what intellectual disability is, then looks into the barriers faced by people with ID when they go into hospital. The chapter then explores the use of hospital health passports by people with ID and explores the application of standards to the passports.

Chapter 3 presents the design of the research study, which uses both observation and survey questionnaire data to resolve the research questions. It describes in detail how both methods are used to collect and analyze data. The chapter also details ethical considerations of the study.

Chapter 4 is divided into two sections pertaining to the two methods of collecting data. Both sections detail the results of each method.

Chapter 5 discusses the results with the aim of resolving the research questions.

Chapter 6 presents the conclusions of the study. It details what has been learned from the study in relation to a standard hospital health passport. This chapter also includes the limitations of the study and future areas of research.

Chapter 2 Literature Review

2.1 Introduction

People with Intellectual Disability (ID) have difficulty gaining access to the most basic rights enjoyed by people without disabilities. Healthcare is one area where evidence is mounting that services are continually failing to meet their needs. Good quality healthcare is demanded by everybody, but people with ID encounter barriers that prevent them from accessing those services available to the rest of the population. People with ID have complex health needs that require the current health system to adjust to meet these challenges. Previous models of support for people with ID are designed to support them within organizational and institutional services but there is now an increasing shift to a community based model. This move to community living will increase demand for general public services. The transition of people with ID from institutions to communities has meant that, increasingly, professionals without specialized knowledge of the health needs of adults with ID are asked to care for them (Sullivan et al. 2006). There are reports worldwide that the challenge of providing specialized services for people with ID is not being met and local services are still incapable of providing optimal interventions and outcomes.

This review of literature is set out first to explain what is Intellectual Disability. This will address the range of problems and opportunities a hospital healthcare provider will encounter when a person with ID enters a hospital. Following this are specific issues that are important for people with ID in accessing hospital services. It highlights areas where the hospital and healthcare providers can improve their services to facilitate the needs of people with ID. The concept of the hospital health passport is then introduced and described including its availability and use. The case for a standard hospital passport is then put forward and the implications of a standard hospital passport is explored. Technical issues regarding the ability of the current healthcare IT infrastructure to implement a standard passport are also explored.

2.2 Intellectual Disability - Definitions and Description

The World Health Organization (WHO-Europe n.d.) defines the term Intellectual Disability as " a *significantly reduced ability to understand new or complex information to learn and apply new skills.*" The WHO further state that this is an impairment in intelligence that reduces the ability to cope independently in society. It is considered to be chronic and often co-occurs with other mental conditions such as depression, attention-deficit/hyperactivity disorder and autism spectrum disorder (APA 2013). For the term to be used to diagnose an individual, these reduced abilities or impaired intelligence should have started before the age of 18. This cut off age is accepted by the American Psychiatric Association and the American Association on Intellectual and Developmental Disabilities as the time that the development period ends. A person who exhibit impaired intellectual functioning after the age of 18 would be caused by brain injury through accident or illness and in the case of older people, from dementia (Foreman 2009).

There are three areas or domains of adaptive functioning that ID impacts on an individuals' ability to cope with everyday tasks (APA 2013).

- Conceptual domain - language, reading, writing, math, reasoning, knowledge and memory.
- Social domain - empathy, social judgment, interpersonal communication skills, making and retaining friendship.
- Practical domain - personal care, money management, recreation and organizing work tasks.

Intellectual Disability is increasingly being used worldwide to replace other terminology such as "*mental handicap*", "*mental retardation*", "*developmental disability*" and "*learning disability*". Although some of the earlier terminologies previously used are now considered politically incorrect in society today, there are still organizations that use them. Mental retardation is still used by ICD 10 in its coding for classification of diseases but there are clear tangible signs that it will soon be replaced by Intellectual Disability in the next iteration of ICD 11 (Salvador-Carulla et al. 2011). The upcoming fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is revising the term to encourage more comprehensive

patient assessment (APA 2013). The table below (table 1) shows the four categories used in Intellectual Disability and the corresponding IQ score and equivalent mental age in years. It must be emphasized though that IQ score is not the defining factor of a person's overall ability but should also consider the severity of impairment on adaptive functioning (APA 2013).

Table 1. Categories of intellectual disability (ID) and corresponding IQ score and mental age

Category	IQ Range	Equivalent Mental Age
Mild	50-69	9-12
Moderate	35-49	6-9
Severe	20-34	3-6
Profound	Less than 20	Less than 3

2.3 Health of people with ID

2.3.1 Aging population

Almost all countries worldwide are showing signs of an increase in life expectancy. Although this trend can be related to better health policies and socioeconomic development, the WHO (WHO n.d.) warns of the challenges for society to adapt to provide older people with security and maximize their social participation. A similar trend in life expectancy is also evident with people with ID. The National Intellectual Disability Database of Ireland highlights that the number of people with moderate, severe or profound disability has increased by 41% since 1974, a trend similar to the general population (Kelly & Kavanagh 2011). This changing age profile will inevitably have implications to future health service planning.

One of the strategic objectives for the "*Towards 2016*" document set up by the Department of Health of Ireland for the National Disability Strategy specifically aims to provide every person with disability with access to appropriate care and health in

conformity with their needs and abilities (*Towards 2016 Strategic Document 2009*). Policies like these aim for better healthcare for all, but translating them to effective groundwork to improve the health of people with ID is challenging. The downturn in the economy has compounded the difficulty of providing for people with ID, with many services cut such as respite care and other specialty services.

2.3.2 Health needs

The health needs of people with ID are complex and they represent a patient group that is poorly understood. Many aspects must be taken into consideration such as syndrome specific health risks or the extent of the central nervous compromise with regard to the cause of the intellectual disability (World Health Organization 2000). Studies of people who suffer from Down Syndrome throughout life stages have shown high prevalence of medical problems in children and teenagers (Yam et al. 2008) and adults (Henderson et al. 2007). Associated impairments also need to be taken into account as they are known to impact on their health needs. People with ID are also more likely to have pre-existing co-morbidity which in turn increases their risk to develop secondary health conditions (van Schrojenstein Lantman-de Valk & Walsh 2008). A study in Finland of 461 people with severe and profound ID have found that 92% had one to six of the identified associated impairments (Arvio & Sillanpää 2003). These impairments are speech handicap; motor handicap; epilepsy; autistic features; progressive nature; behavioral disturbance; blindness and deafness. The study points out that the most common impairments are speech defects, epilepsy and motor handicaps with 24% having all three.

Leading causes of death for people with ID are also different compared to the general population. The leading cause of death for people with ID is respiratory disease followed by cardiovascular disease related to congenital heart disease (*Health Needs Assessment Report, 2004*). A report on the health status of people in Ireland (2008) determined that the leading cause of death is circulatory system disease followed by cancer. It reports also that deaths from cancer is increasing and deaths from circulatory disease falling. This is already true in Scotland where the leading cause of death now is cancer followed by ischemic heart disease (*Health Needs Assessment Report Scotland, 2004*).

The leading type of cancer as cause of death for people with ID also differs from the general population. Gastro-intestinal cancer has a higher incidence in people with ID, whereas cancer of the lung and prostate are higher in the general population (Cooke 2007). This can be partly explained by lower rates of smoking and high rates of untreated gastro-esophageal reflux disorder in people with ID (*Health Needs Assessment Report Scotland, 2004*).

2.3.3 Communication

An integral part of an assessment process is communication and this is a problematic area for people with ID. Their abilities vary greatly from one individual to another including their ability to understand and express themselves. This causes issues in all areas of healthcare including health promotion or disease prevention. Those with the severe to profound levels of ID may not have any speech at all and those with the milder ID can speak but may not have the necessary capacity to convey what they mean to say. They may express their discomfort through changes in behavior or personality, facial expression, body language or changes in routine (Davies 2008). Clinicians who are not familiar with how a person with ID express themselves may not associate such cues to a health concern. It has to be remembered that communication is a two way process and it is the responsibility of the healthcare professional to adopt approaches to communication that is appropriate for somebody who has ID (*Health Needs Assessment Scotland, 2004*).

People with ID also use different tools to help them communicate. Augmentative or alternative communication (AAC) is an umbrella term used to describe a range of methods from pictures and communication boards to electronic gadgets that generate speech to help people with ID communicate. They are designed to enhance communication methods, in addition to their usual gestures and vocalizations (Noens & van Berckelaer-Onnes 2004). Familiarity with how a person communicate will be beneficial in providing personalized care.

2.3.4 Pain

There are many problems in pain management for people with ID. If they cannot express their pain verbally, they may express it in other ways which may be different or unique to each individual. A systematic review (de Knegt et al. 2013) that focused

on identifying behavioral indicators of pain in people with ID have found fourteen categories that can be used to indicate pain. The researchers though cautions the interpretation of their findings because some of the categories consisted of contrasting behavioral indicators. The authors further point out that certain factors may influence pain expression, it is difficult to ascertain if the observed behavior is caused by pain or other stimuli such as fear or stress. One of their recommendations, besides being aware of the persons pain indicators, is to use standardized instruments especially for people who are not familiar with people with ID.

The experience of pain is subjective and sensitivity to pain has long remained a challenging clinical problem (Coghill 2010). People with ID are acknowledged to experience more painful conditions than the general population (Department of Health 2001) but they may be unable to express pain verbally. Most assessment procedures in healthcare require self-reporting measures, which rely heavily on history or response to pain, and use this information to provide the appropriate care (Foley & McCutcheon 2004).

2.3.5 Diagnostic overshadowing

Changes in behavior are important indicators for possible signs of pain or distress. Unfortunately there are times that these changes in behavior are not connected with the discomfort a person with ID is experiencing. One explanation for this is 'diagnostic overshadowing'. This refers to clinicians making assumptions about a persons' presenting problems and associates them as a feature of the intellectual disability. Investigations are often delayed and sometimes there are no investigations which lead to prolonged suffering or death (NPSA, 2004). This reveals an overall lack of training and skills that often lead to a wrong diagnosis or no diagnosis of a condition that needs attention (Fearn 2007). One reason for this is that many clinicians working in mainstream health services have little or no formal education pertaining to ID in general and their needs in particular (DHSSPS, 2005).

People with ID also have some behaviors that can be a problem for hospital, staff such as aggression or self-injury. With the range of behaviors and difficulty of differentiating the cause of the behavior, it may lead to symptoms such as pain not being identified. All possible physical, environmental and emotional factors such as

pain, stress or grief must be ruled out before considering a mental problem (Sullivan et al. 2006). Family members or longtime carers are a valuable source of information for clinicians, often they have personal knowledge and experience in detecting subtle changes in behavior that may easily go unnoticed.

There are also misconceptions or other assumptions that often result in symptoms not being managed properly. There are some who view that people with ID have a high pain tolerance or do not feel pain (Foley & McCutcheon 2004). Although there are instances where some individuals may be insensitive to pain due to impairments in their neural pathways (Nagasako et al. 2003), it could be that they just have an atypical response to pain. High tolerance of pain associated with certain causes of learning disabilities may result in carers not being aware of a health need (*Health Needs Assessment Report*, 2004). Clinicians find it difficult to obtain a thorough assessment with patients who are unable to co-operate with conventional forms of communication (Davies 2008). In most cases, the carer provides the information during the assessment process and must know the person very well to be able to give accurate details such as reaction to pain.

2.4 Access to health Services

People with ID generally experience more difficulty in accessing health services than the rest of the population. The services that they are able to access are of poorer quality, not only due to the complexity of ID but also due to many barriers and inadequacies of the current health systems (Sixsmith et al. 2005). There is a growing emphasis on inclusion in current health policies but people with ID are still experiencing inequalities accessing healthcare services in general. A study on the experiences of people with ID in general hospitals and their carers show that there is a lot of dissatisfaction with the care and service they receive (Lewis & Stenfert-Kroese 2010).

There are some reports of negative attitudes towards people with ID that exacerbate the health inequalities that they experience (Lewis & Stenfert-Kroese 2010). Studies have shown a link between the quality of care delivered by clinicians to their attitudes

to specific client groups such as those with physical disabilities (Courtney et al. 2000) and mental illness (Thornicroft et al. 2007). People with ID will take time to undertake a detailed assessment and this can be challenging in a busy hospital environment. This can be critical especially in areas such as Accident and Emergency (A&E) where reports indicate that the assessment process can take up to four times longer for people with ID than the general population (Morad & Merrick 2005).

2.5 Issues of consent

The principle of consent is an important part of medical ethics and the international human rights law (NHS Choices 2012). The ethical rationale behind the importance of consent is the need to respect the service user's right to decide what happens to their body (National Consent Advisory Group 2013). A person must give permission to receive any type of medical treatment. Consent must be valid, voluntary and informed and can be given verbally, non-verbally (nodding to indicate they are happy with the decision) or in writing (NHS Choices 2012).

In Ireland, the Non-Fatal Offences against the State Act (1997) states all persons over the age of 16 can give consent for surgical, medical and dental procedures. The amount of information needed by an individual depends on several factors such as their level of knowledge and understanding about their condition and their ability to understand the information provided (National Consent Advisory Group 2013). The National Consent Policy (2013) states that service users should be given time and support to make decisions themselves, and it must not be assumed the somebody lacks capacity because of communications difficulties, intellectual disability or cognitive impairment.

At present there are no specific procedures for making medical decisions on behalf of people with ID (Inclusion Ireland 2008) nor any legislative framework to govern those who lack capacity to give consent (National Consent Advisory Group 2013). The responsibility then rests with the health professional to consider what is in the person's best interest if the person does not have the capacity to give consent.

Health professionals may not have the skills to communicate effectively with person with ID. A healthcare professional may not have the time to establish a relationship in a very challenging environment such as the A&E. Communication difficulties are considered a particular challenge specially to understand needs, inform patients and gain consent (Sowney & Barr 2007a). All reasonable ways of determining capacity must be taken before assuming that a person lacks capacity, unfortunately this is not always the case. This often leads to a situation where the healthcare provider would rather get information from the carer or family member. The person with ID would be excluded from the conversation about their healthcare and may not be asked directly to consent to treatment (MENCAP 2004).

2.6 Improving support

There is still little known about the experiences of clinicians in acute general hospitals or the challenges they encounter in providing care to people with ID (Sowney & Barr 2006). Review of the literature regarding the experience of people with ID in the hospital setting seem to be lacking as well. There are some groundwork and analysis with respect to access to GP service and primary care as a whole but this doesn't seem to be the case in secondary care. Comprehensive studies in hospital settings, such as presentations in emergency departments, that examine the demographic, intellectual disability, health, and adaptive status factors are non-existent (Venkat et al. 2011). More could be done in the area of research to bridge the gap in knowledge to help practitioners provide proactive and responsive strategies.

Health services should make reasonable adjustments to provide individualized care that are informed by the knowledge of health vulnerabilities of people with ID. Services will probably have to introduce new policies and procedures taking into consideration the uniqueness of each individual to promote a better hospital experience. Complaint procedures must also be followed up and concluded in a reasonable time frame. Investigations will point out faults in the system and hopefully lead to changes for the better. Sometimes the process is too complex that leads complainants to feel discouraged (Fearn's 2007).

The Accident and Emergency (A and E) is one area of healthcare that must make certain adjustments to meet the challenges people with ID bring. It is a stressful place to be in, and in general manage patients according to urgency and perceived need like medical, surgical or psychiatric through a process called triage (Bradley 2005). The nature of an A&E requires information to be collected under a relatively short period of time but there are indications that the assessment process may take as much as four times longer for people with ID than the general population (Morad & Merrick 2005). Literature regarding the experience of people with ID in acute hospitals are growing but their experience within emergency departments are less mentioned (Sowney & Barr 2007b). Research in the use of A&E's by people with ID is limited because the presence of ID is not systematically recorded in existing ED data (Lunsky et al. 2011). The first North American population data study on ED use by people with ID in 2011 linked several data holdings to create a cohort and found that people with ID have higher rates of ED use than people without ID (Lunsky et al. 2011).

The National Emergency Medicine report of Ireland (2012) pointed out that the Emergency Department needs competent staff to care for people with ID. It requires specific educational preparation that includes:

- the need to understand what Intellectual Disability is;
- the need to understand potential associated physical and behavioural problems;
- the need to understand what specific support patients require;
- exploration of effective communication methods for this group;
- understanding why and how to tailor assessment for these patients and have relevant tools available;
- awareness of who to contact for further information/advice/support;
- ensuring they are up to date on relevant legislation in relation to rights of person with ID.

Some recommendations in overcoming these deficits may be participating in an awareness program that educates the clinician regarding specific topics such as nature of the disability, conditions and associated health problems, communication issues and management issues (Sowney & Barr 2006). The National Emergency

Medicine Program report (2012) in Ireland have explored use of patient passports for people with ID to make the emergency department experience effective and efficient. The report considers the passport to hold enough detail for the person to feel safe and understood and will help achieve its aim to improve the safety and quality of care in emergency departments.

2.7 The Hospital Health Passport

Organizations catering for people with ID are increasingly using hospital health passports as a means of communicating vital information when a person with ID comes into contact with an acute general hospital. It contains important information like current medication and health history but differs from a health summary as they also contain information such as methods of communication and the person's preferences. It provides a good overview of the person and can be a valuable source of information for healthcare professionals about a person's method of pain expression as well as important idiosyncrasies arising from an individual's disability (Higgins 2009). The passport will lead health professionals to understand people with ID and treat them in a personalized and dignified manner. It is designed to travel with the person as they navigate through the hospital system and educate health professionals to see the person and not their disability (Blair 2010). It is acknowledged that one of the biggest risks to patient safety occurs when the patient passes across the "*boundaries*" of care such as from primary to secondary care (Klingner & Moscovice 2012; HIQA 2012) and the passport can be part of the provisions in providing safe hospital care. Information should accompany the patient along the entire care pathway (HIQA 2013).

Worldwide there is evidence of use of hospital health passports. In Canada, the Hospital for Sick Children research center provides an online facility where they can fill in a form and either print or email the passport. It is created by Miriam Kaufman (Kaufman n.d.) to be used when visiting a new health professional or the emergency department or transitioning from children's services to adult services. Besides developmental disability, the website also caters for passports for more than 50 other medical conditions such as asthma and kidney disease.

A published document on the health indicators for people with ID in New Zealand (Ministry of Health 2011) reported on the trial of a health passport to help health professionals working in hospitals to provide better care for people with ID. By 2013, the health and disability commissioner are working with health boards to introduce the health passports to both hospitals and consumers on a nationwide basis (Health and Disability Commissioner n.d.). The passport is available for download on the commissioners website.

The UK appears to be leading the way in the use and advocacy of the hospital health passport. A search through many NHS hospital websites reports use of hospital health passports. The passports ranges from a one-page document through to several pages, with color codes and an easy read format.

In Ireland, several passports are also being used. The Mercy University in Cork has developed and copyrighted their own passport but adapted them for children with multiple disabilities and complex health needs. One ID service provider collaborated with a major Dublin hospital to create their own passport. It covered eight pages that formed part of a comprehensive package. Other ID organizations adopted a hospital passport introduced first in 2008 in St. Georges hospital in London. This is a collaboration of several teams and NHS trusts and is about nine pages. It is also color coded like traffic lights with red code for "must know" information, amber code for important information for the person and green for likes and dislikes. This seems to be the most popular, besides being adopted by several UK services , it is adopted as well in parts of the US, Canada, Australia and translated in several European countries (Blair 2011).

People with ID also appear to be interested in using hospital health passports. In a study of people with intellectual disabilities experiences of treatment by hospital staff in the UK (Dinsmore & Higgins 2009), those participants who didn't have a passport expressed willingness to own a passport. They believe that possession of the passport would have a positive effect on their future hospital experience.

The hospital health passport is still relatively new in relation to its application to help people with ID communicate and negotiate a better hospital experience. Research studies regarding use of passports and its effect to improving the hospital care cannot yet be considered robust. There are no published research studies found in

Ireland. A nursing master's thesis by Gavino (2013) from TCD is the only one found so far. The thesis by Gavino (2013) interviewed eight nurses who had previous experience of caring for patients with ID who possessed a hospital passport. All participants of the study agree that the passport alleviated the challenges and difficulties met by the nurses when caring for the person with ID.

A PhD thesis (Glaysher 2009) from the UK developed and implemented a hospital passport for people with ID. It looked at whether the use of hospital passports would raise awareness levels of staff in hospitals regarding the needs of people with ID. Not only did the study raise hospital staff awareness, it has also shown that people with ID felt the passports supported communication and improved overall care experience.

The hospital health passports are endorsed by various organizations, government agencies and hospitals. Although they promote good practice, they have no legal status and are only as good as the person completing them (Brodrick et al. 2011). This requires that the person completing the passport know the person very well to be able to communicate the correct information. Procedures will also have to be put in place to regularly update the passport as changes happen over time. There are also some worries regarding the length and content of some of the hospital passports. Broderick et al., (2011) describes the development of a one-page passport in the UK. Their working group are concerned that the other passports are not sufficiently user-friendly. They point out that if the document is not concise, it may not be completed appropriately or hospital staff may not have the time to read and process the information effectively.

2.8 Standards in healthcare

2.8.1 The need for standards

Standards, in general, serve as a basis for planning and managing services, it also measure improvements, address gaps and deterioration of quality and safety of services (HIQA 2012). At present, information contained in the passports do not conform to any national or international standard and vital information could be

lacking or saturated with unnecessary information. Without a developed coherent and integrated approach to health information, documentation is poor and information can be lost (HIQA 2013). This means that information are still fragmented and may not meet the requirements of healthcare professionals in the hospital.

A standard data set for the hospital passport will have to be developed based on the evidence of national and international best practice to help ensure quality and safety in healthcare. It will help bridge the gap in communication and understanding to deliver care that is both personalized and dignified. Development will require consultations with special interest groups, service users, healthcare professionals and the public driven by standards development organizations. An agreed standard minimum data set for hospital passports will ensure that all necessary information is available and pave the way for high quality data sharing. It is important to have high quality information available to a healthcare professional as this will enhance the quality of care provided to a person with ID. The inability to share information leads to unnecessary duplication of tests and delays in patients receiving appropriate treatment (HIQA 2013).

The Health Information and Quality Authority (HIQA) is the body responsible for setting standards for health and social care services in Ireland. They provide a framework for providers for the ongoing development of person-centered residential services, focusing on outcomes that empower people with disabilities to participate, contribute and realize their full potential (HIQA 2012). HIQA has provided some points that the hospital health passport will contribute to achieve this outcomes.

- respecting their autonomy, privacy and dignity and promoting their rights
- facilitating them to exercise personal choice in their lives
- safeguarding and protecting them from abuse
- providing them with accessible information and assessment to ensure appropriate support services are made available

The recommendations from a report by the Royal College of Psychiatrists (Hassiotis et al. 2012) in the UK stated that key information about people with ID should be available to health services outside working hours which means information-sharing

with other organizations. They went on to further state that a minimum data set is essential and should be accessible at all times but acknowledge that it may be difficult due to a variety of electronic care records software used by different organizations. Reports like this further emphasizes the need for a standard, to gain high quality information and ensure a better chance of future information sharing.

2.8.2 Composing standard data sets

So how then is a minimum data set composed for a hospital health passport? The WHO states that “*a minimum data set means that only the least, most essential information is gathered and used*” (World Health Organization 2005). There could be three options in creating a minimum data set for a standard hospital health passport. First is to create and develop one's own data set. Kane, Bartlett, & Potthoff (1995) states that need, tradition, professional judgment and empiricism, must influences how items are chosen for a data set. The second option is to adopt a passport from other reputable jurisdictions. This is done by some Irish ID providers when they adopted the St. Georges hospital health passport from the UK. This strategy can save a large amounts of time and resources. The third option, which is the adopted methodology by the study, is similar to how HIQA (2013) developed the National Standard for Patient Discharge Summary Information. Other data sets, hospital passports for this study, are analyzed to develop a list of information that are later consulted with stakeholders. HIQA (2013) warns of creating standards trying to include the information requirements of all specialties, HIQA argues instead in limiting the scope to include requirements which are common across the majority of clinical specialties.

2.8.3. Benefits of having Standard Hospital Health Passport

- ID Providers - Implementation of standards will mean a reduction in the proliferation of passports developed by different ID providers. A standard passport will help ID organizations plan and improve services. A standard hospital passport can provide the groundwork for electronic passports that increases efficiency of information transfer. Staff caring for people with ID will not have to rely on memory if a comprehensive standard hospital health passport is available when bringing people with ID to hospital.

- Hospital - Hospital professionals will have a reliable source of information when providing care for people with ID. A standard hospital passport will mean that information sent to secondary or tertiary care will be consistent and standardized across organizations and services. Transfer of information will be more effective and will assist in making sure that the correct data is coded into Hospital Information System (HIS) or Electronic Patient Record (EPR).
- Patient with ID - Standardization of information contained in a hospital health passport will improve the quality of the data communicated to hospital staff. The result is a more personalized and dignified treatment and care. If there is a facility for electronic transfer of information, the information contained in the passport can be accessed before the person arrives in hospital to prepare hospitals for any specialized requirements.

2.8.4 Implications of standards in healthcare

The healthcare industry is lagging behind other industries such as the financial industry in terms of interoperability standards (Boucher et al. 2006). Proof that international standards could work is the use of debit cards where vendors are operating globally. There are still many barriers to interoperability standards in healthcare such as lack of support from appropriate policies and regulations to the complexity of the healthcare system. All must work together, hospitals, doctors, nurses, vendors, policies, insurers, not just single entities, to make it work. Incentives need to be established to encourage adoption of standards locally and supported by legislations and policies.

In the US, a study (Walker et al. 2005) exploring the economic implications of a fully implemented healthcare information exchange and interoperability standard using a cost-benefit model, found a compelling business case to fully implement such a system. Although the study mostly looked at the economics, the authors suspect that the clinical payoff in improved patient safety and quality of care could dwarf the financial benefits that are projected.

Healthcare is information-intensive and the inability to connect information throughout the system is extremely costly, both in terms of human life and economics (Boucher et al. 2006). Indeed, HIQA (2013) estimates that up to 30% maybe spent in Ireland's total health budget either handling, collecting, looking for

and storing information. When critical information is stored in unconnected systems, the information can't move to where it is needed for healthcare professional to make better decisions. There is poor clinical decision support to help deliver better and safer healthcare. At present, the current ICT structure of Ireland's health and social services are highly fragmented and there are major gaps and silos of information (HIQA 2013). One result of this fragmentation is having to provide the same information every time you go to another provider.

HIQA (2013) recently published a national standard for patient discharge summary and acknowledges that development of the standard is an important step in improving the whole care pathway. They state that an incomplete or delayed discharge summary places the healthcare professional in primary care at a disadvantage. It could be argued that having a standard hospital passport is more critical to have completed and developed as the person with ID is still going into hospital.

2.8.5 Adoption of standards

One of the earliest adoption of standardized assessment tools to guide care planning is the nursing home Resident Assessment Instrument in the US. The RAI minimum data set is implemented in 1991 and is required to be used on first admission to a nursing home to assess and develop plan of care (Hawes et al. 1997). It is developed in response to concerns that existing regulatory systems at the time are ineffective in improving the quality of nursing homes. It is mandated by the US Congress that the RAI should be uniform and comprehensive and focus of the developers are on facilitating communication and problem-solving among a multi-disciplinary team by creating a common 'language' and understanding of the client (Hawes et al. 1997). Evaluation of the results, including the testing of the RAI's reliability and validity, is performed after four years and showed improvements in the quality of care (Hawes et al. 1997). This is one good example of standardization that has broken barriers in universal acceptance in the clinical setting. A study by Sgadari et al. (1997) describes how the RAI is tested and produced excellent reliability in the USA and six other non-english speaking countries. The study has shown the importance of standard data sets to produce reliable data in research as comparing

data in different countries has proven difficult since the names of institutions vary greatly and have different meanings to different cultures (Sgadari et al. 1997).

Another data set leading in the field of standardized tools is the UK Mental Health Minimum Data Set (MHMDS). The MHMDS covers services provided in hospitals and outpatient clinics in the community (Anon n.d.). It boasts national consistency, and brings together information that is compiled into a single patient record. The data set is currently being expanded to include intellectual disabilities.

Standards should, in general, build on each other to make each set of standards necessary for the other. The following areas in healthcare (Nelson 1997) will have to be standardized, from basic to complex, that will result in a set of standards to finally permit full information transaction .

- Terminology - There must be agreement on clinical terminologies and definitions, such as "*Intellectual Disability*" or "*Hospital Health Passports*" to make data useful in multiple settings. The upcoming revisions of the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) are steps towards the standardization of the term "*Intellectual Disability*". The issues in the use of terminologies does not just affect communication between professions such as between doctors and nurses and social workers but within the professions themselves. For example with Nursing where the American Nurses Association currently has approved thirteen standardized languages that support nursing practice (Rutherford 2008).
- Information Model - Although agreement on terminology is paramount, there has to be agreement on how the data is used, processed and structured. If a person with ID comes into contact with A&E, there should be a process for the records or data to be combined with his own GP's ongoing record or with the service providers records.
- Connectivity - The efficient transfer of communication from one health system to another will be the next requirement after both model and terminologies are agreed upon. Standards in connectivity will let a hospital or GP system access or add to the persons' data kept in a service providers data storage.

- Policies - The appropriate management and use of data will need to be put in place once all previous requirements are met. Issues over privacy and confidentiality will have to be hurdled to provide confidence in the system. That data are available to provide the best possible care but also that privacy of individual is protected. The reliability of the system and quality of the data must also be guaranteed to make sure mistakes do not happen. That the correct data is collected and associated with the right individual or patient.

As more and more areas in healthcare slowly become computerized, so too are the processes from all these systems. The standards in all areas discussed need to work together to make it function properly. It is unlikely or even impossible for medicine, nursing, or any health-care related discipline to implement something like electronic documentation or EPR's without something like standardized language or vocabulary to describe key components of the care processes (Rutherford 2008). Efforts such as standardization of the terminology used in Nursing is being evaluated by The Committee for Nursing Practice Information Structure (CNPPII) by determining if a term meets certain criteria. One step further into electronic documentation is the Nursing Information and Data set Evaluation Center which accredits if terminology used by a vendor conforms to standards pertaining to computerized information systems.

The example of the RAI minimum data set is a good example of standards being implemented internationally but there are disagreements whether standards should be developed at international or national level. Arguments against use of international standards vs. national standards in healthcare are still being debated upon (Barr 2008). Advocates for national standards indicated that international standards are not flexible and are sometimes not coherent, meaning they are difficult to change and maintaining them are very complicated. They further state that features that are relevant to the US may not always be relevant to other parts of the world.

2.9 Conclusion

The review of literature explains the nature of ID and suggests that people who have ID are more likely to be admitted to hospital than people without ID. The barriers encountered by people with ID regarding access to hospital services are identified and explains how hospital health passports are used to overcome these barriers. The review of literature points out that there is not a vast evidence base regarding the use of hospital health passports in acute general hospital by people with ID. But even with the lack of studies for the use of hospital health passports, there are many countries and services who have endorsed them for people with ID. The idea of a standard hospital health passport is put forward and explains how to achieve standardization. Rationale for a standard hospital passport are explained including benefits to people with ID and hospital professionals. The implications of a standard hospital health passport regarding future IT services are explored.

The hospital health passport is a vital tool for people with ID in overcoming barriers to accessing hospital services. It is essential then to make sure that a standard is set for hospital health passports to ensure quality and safety for people with ID. This study analyzes available hospital health passports and aims to create a standard based on the requirements of hospital professionals. The following chapter discusses the methods used in the study.

Chapter 3 Methodology

3.1 Introduction

This chapter presents and discusses the rationale for the research design and methods used for this dissertation. The methodology considers the logic behind the techniques used in the study (Kothari 2004). This chapter first explains a description of the research strategy which uses both qualitative and quantitative data. Next, the selection of participants using purposive sampling is explained. Following the method for sampling, the strategies for collecting data using ethnographic observations and survey questionnaire are explained, including the design of the questionnaire and analysis of the data. Lastly, ethical considerations and issues to access of the study sites are addressed.

3.2 Research aim and questions

The overall aim of this study is to determine the minimum data required by doctors and nurses for a standard hospital health passport for people with ID . The research also set out to answer the following questions.

- Do doctors and nurses find taking care of people with ID more difficult compared to people without ID?
- Do doctors and nurses require more background information to care for people with ID?
- What are the implications of a standard hospital passport in relation to future Hospital Information Systems for people with ID?
- Is there a difference between the information required by doctors and nurses for the hospital health passport for people with ID.

3.3 Research design and approach

The study uses both quantitative and qualitative data to resolve the research questions and aim. Mertens & Hesse-Biber (2012) believes that quantitative and qualitative data can be mixed for the purpose of illustrating a more complete understanding of the phenomenon being studied. Combining both types of data in a study is called a combined or mixed method. Having the different data sources allowed for triangulation of data in the study. The review of literature show that there is a limited number of research studies regarding the use of hospital health passports. This strengthened the reason for employing a mixed method approach.

Ethnographic observations and survey questionnaires are the primary tools for collecting data. The ethnographic observations are narrated as case scenarios. The observations provide a description of situations when a person with ID comes into contact with hospital professionals. It also provides a platform for learning about interactions in a natural setting. Numerical data are generated thru a survey questionnaire. The opinions and other factual information of respondents are gathered in order to classify and relate them through statistical methods.

There are many controversies and still unresolved questions in the application of mixed method research (Denzin & Lincoln 2011)(Mertens & Hesse-Biber 2012). Although both qualitative and quantitative methods have advantages and disadvantages (Teddlie & Tashakkori 2009), combining them offers a unique insight into the increasing complexity of research problems relating to health and wellbeing (Andrew & Halcomb 2009).

3.4 Sampling method

Purposive sampling is utilized to select participants in this study. The population consists of registered nurses and doctors working in three tertiary hospitals in the Dublin area. Although there are general guidelines regarding sample size and population, this study tried instead to achieve optimal exploration rather than trying to meet a sample size. Polit and Beck (2004) explains that the guiding principle is data

saturation, where sampling is to the extent that no new information is being discovered and redundancy is achieved, demonstrating a convergence of opinion.

Participants in the study are either a registered doctors and nurses who work either in the A and E, outpatients, medical or surgical ward. The criteria's for inclusion and exclusion are given in table 2. Doctors and nurses are selected as they are identified as the most likely to use and benefit from a standard hospital health passport. Specialist wards are excluded from the study as people with ID are usually accompanied by carers or family members if they are admitted to these areas.

Table 2 Criteria for inclusion and exclusion of participants in the study

Inclusion Criteria

- A participant must be either a registered doctor or nurse.
- A participant must work in either the A and E, outpatients, medical or surgical ward.

Exclusion Criteria

- Doctors and nurses who work outside of the listed areas.
-

Initially the participants were proposed to be recruited through hospital research channels but for reasons explained in the Ethics section, personal and professional networks were utilized instead to recruit participants. This is either referred to as chain referral sampling or snowball sampling. A sample population is created through a series of referrals that are made within a circle of people who know one another (Kotz et al. 2004). Sampling through the professional regulatory organizations such as AN Bord for nursing was also considered. An Bord has a facility for research sampling where they can distribute questionnaires to their members for a fee. Although this is a good alternative, this did not guarantee that it

will fulfill the inclusion criteria for the study. Many nurses work outside of hospitals such in the ID sector, clinics and nursing homes.

3.5 Data collection and analysis

3.5.1 Case scenarios

The scenarios detailed in the results section are observations based on actual events. Care has been taken to make sure any identifiable information are removed or replaced. Names that appear are fictitious to preserve anonymity.

The observations provide a description of situations when a person with ID comes into contact with hospital professionals. The observations highlight the complicated nature of ID and the challenges ID carries. The case scenarios borrows from 'naturalistic research' where data are observed in natural settings and not experimental ones (Mays & Pope 1995). The observations are from the point of view of a carer attending hospital with a person with ID.

The use of case scenarios in the mixed method approach lends itself well to the exploration of observed deficits of care, then converged with quantitative data to generate conclusions. The case scenarios are retrospective or 'a look back.' Other staff nurses who works in the same area were consulted before writing up the case scenarios. This confirms most of the observational data and diminishes the researchers bias.

3.5.2 Questionnaire design

Initially, a search for hospital passports that are developed nationally and internationally was conducted. All in all, there are 6 hospital passports obtained, 5 are freely available for download from the internet and one obtained through a professional network. The hospital health passports collected are endorsed or used by hospitals, ID organizations or government ministries. Analyses of other data sets to develop a list of items of information is similar to the methodology used by the Health Information and Quality Authority (HIQA) of Ireland (HIQA 2013) when it developed its initial draft for the National Standard for Patient Discharge Summary.

After development of a list of items, HIQA consulted a broad range of stakeholders, including hospitals and primary healthcare providers to comment on the draft. The range of comments come from both organizations and individuals in their personal capacity. It was contemplated to include hospital organizations as respondents but it might not be feasible with time constraints. In the end individuals, doctors and nurses, are selected because they are the end users of the information.

The research instrument is designed as a two part questionnaire. The first part comprises of demographic questions and several probing statements regarding difficulties encountered by hospital professionals in caring for people with ID. Demographic questions include profession, length of work experience and experience working with people with ID. Four probing statements are consolidated in question 5 (See Appendix). Respondents were asked their degree of agreement or disagreement with the statements in a likert scale. The first two statements in question 5 (5a and 5b) are ordered to minimize error. The order is fashioned semantically for their sequence of meanings. This is to prevent any effect on the measurement by influencing the cognitive processes triggered by the series of questions (Krosnick & Presser 2010).

The second part is comprised of specific items information that hospital staff may or may not require while caring for a person with ID. These items of information are from the hospital passports explained in the beginning of this section. All items from each of the hospital passports are listed individually and compared with each other for duplication. Some items are easy to list such as name or date of birth or current medication as they are the same with each passport. Others are not straight forward. One of the hospital passports had an item listed as "*activities of daily living*" where the person filling it will provide a narrative description of the item. Other hospital passports detailed each activity of daily living such as eating and drinking, grooming, sleeping, etc. The latter way of detailing the items are adopted for the questionnaire. It will let the respondents determine which items will be important for the standard hospital passport. There are 42 items identified then divided into three groups or themes. The three groups are; identifying information, health information and personal information. A review of the recently published National Standard for Patient Discharge Summaries (HIQA 2013) provided an insight regarding the level of detailed information communicated to primary healthcare professionals to improve

quality of care after discharge. HIQA has also grouped the items in the published standard.

A facility for extra items including the rating scale is placed in the end, in case the respondents have other information they feel is important to be added to the passport. The respondents are asked to rate each item in a five point scale as well from very low importance to very high importance. A comment section is also provided for the participants.

The questionnaires are distributed primarily on paper but a version is also published online. Lime Service is chosen as the online platform. It appears to offer better functionality and may cost less overall against other online platforms. The cover letter with the paper questionnaire offers respondents a choice as to which platform they prefer to fill in, but they are asked to choose only one method. It is presumed that offering a choice would maximize response returns.

3.5.3 Pilot study

Problems can arise during the course of the study so it is vital to do a pilot study (Vivar et al. 2007). Pilot studies can be a smaller trial run of the major study or trying out the research instrument (van Teijlingen & Hundley 1998). In this research, the pre-testing of the questionnaire was conducted to discover if there are any errors or potential problems with the methods, logistics and the questionnaire itself. The questionnaire was piloted to 5 nurses who were deemed to conform to the inclusion criteria set. Social networks were utilized to identify pilot respondents for speed and convenience. The pilot respondents were asked to point out any question that they feel are ambiguous or confusing. Changes to the questionnaire that arose included cosmetic changes to make the questionnaire easier to work with. A few of the questions were reworded as it is considered by some of the participants to be too vague.

3.5.4 Collection of survey questionnaire

The survey questionnaires were collected with the help of key network contacts. The contacts were also instrumental in contacting respondents and distributing the questionnaires. Contacting participants, distribution and collection of questionnaires lasted 5 weeks. The questionnaire assured each participant anonymity, and no

identifiable information collected. All participants were provided with a cover letter describing the survey questionnaire and the aims of the study.

3.5.5 Data analysis

Data from the questionnaires were analyzed using SPSS. SPSS is one of the most popular statistical software for managing data and calculating a wide variety of statistics (University of Wisconsin 2013). Analysis of the data involved descriptive statistics, cross tabulations, Chi-square test and Mann Whitney U test. Chi-square test is used for categorical variables divided into mutually exclusive groups (Jupp 2006). Mann Whitney U is used to compare differences between two independent groups (example, doctors and nurses) when the dependent variable is either ordinal or continuous, but not normally distributed (Laerd Statistics 2013).

3.6 Ethics and access to study sites

The main priorities regarding the collection and management of data are participant anonymity, confidentiality and security. The respondents were not obliged to participate in the survey. No identifiable data were collected from the survey questionnaire. All respondents were informed that it is voluntary and they can withdraw at any time without penalty. The online survey allowed respondents to exit at anytime, save a partially completed survey and resume later or exit without saving. All data are handled according to the Data Protection Act of 2003.

The proposed data collection sites were three tertiary hospitals in Dublin. These sites are chosen to provide a range of clinical experience and input for a standard hospital passport. The hospitals were contacted for ethics approval. Two of the hospitals responded that the study did not require ethics approval from their own ethics committee but may require permission from the CEO due to two types of professions or respondents. The third hospital required ethical approval.

The office of the CEO of the two hospitals who did not require hospitals were contacted through email. No answer was received after a week so they were contacted through phone. Inquiry was eventually directed to the Nursing department. On inquiry with the nursing department, they could only speak for the nursing profession but they could not speak for the medical doctors. Several phone calls

trying to find a contact person for permission to survey doctors proved challenging and time consuming. One administrative department mentioned that one may have to go look for doctors in the wards.

The third hospital responded after several weeks of being contacted with the application for ethics and required further information and clarifications. This meant waiting for the next round of ethics meetings. While application to the hospitals are ongoing, university ethical approval was being sought. Unfortunately, the university seemed to be content to wait and see if approval is going to come from the third hospital and the hospitals seemed to wait for assurance from the university. Eventually, when the university ethics committee member was pressed to respond, the member started to pick on technicalities that could have been resolved weeks earlier. As the deadline for submissions were looming, amendments to the recruitment of participants were made. Network sampling was added to the strategy to recruit participants in case there were further delays. Ethics approval was received from the university School of Computer Science and Statistical Research Ethics Committee on April 4, 2014. Unfortunately there were too many delays and with a looming deadline that the use of networks and referrals offered quicker access to participants.

Access to hospital staff and ethical approval is a complex undertaking for any researcher. More so if the intended participants are in different professions and are in different sites. There are multiple gatekeepers and different rules to satisfy regarding ethics which meant different research proposals and application forms.

3.7 Conclusion

This chapter presents and discusses how this study is supported by survey and observation methods. The chapter outlined the planning and approach of the research including selection of participants, how data are collected, managed and analyzed. The ethical considerations in approaching this study, and the difficulties in conducting it are detailed. The analysis of the results from the study are discussed in the following chapter.

Chapter 4 Results

4.1 Introduction

This chapter is divided into two sections. The first section is an ethnographic observational narrative based on actual events. There are three case scenarios in the first section depicting fictitious characters who have an Intellectual Disability (ID) and who come into contact with a hospital. It offers an insight into the interactions between hospital professionals and a person with ID from the point of view of a carer. The observations highlight the complicated nature of ID and the challenges it carries.

The second section is feedback from the survey questionnaire that are administered to doctors and nurses (see Appendix). There are 43 questionnaires returned from both professions. Their opinions and other factual information are gathered and analyzed to classify and relate them through statistical methods. Tables, charts and graphs are used to illustrate some of the results.

4.2 Case Scenarios

4.2.1 Introduction

There are three case scenarios in this section, each offering different hospital situation that highlight the complicated nature of intellectual disability and the challenges they present. The case scenarios are narratives of observations based on actual events. Care has been taken to make sure that any identifiable information are removed. Names have been changed to preserve anonymity. All are taken from the point of view of a carer. The first case scenario is located in an Accident and Emergency ward and the last two are situated in the general wards. The case scenarios are retrospective and other nursing staff are consulted to confirm some of the data. This ensures accuracy and integrity of the narrative.

4.2.2 Case scenario 1

Agnes is an older adult with ID and dementia. She lives in a residential care home with similar disabilities. She is non-verbal and needed assistance in all her needs. Agnes did not appear to be herself one day. She is lethargic and appeared to be more resistant to assistance being offered to her. At around lunch time she had episodes of vomiting. She started a temperature, the GP was called and who put her on antibiotics. That evening she started to have more episodes of vomiting and her temperature was rising. An ambulance was called. As she was being prepared, care staff gathered her files that contained both medical and social reports, kardex and daily reports, information that the hospital may need. Agnes is accompanied by one of the day staff. On the way to hospital, as the paramedic was filling their report forms and the paramedic asks the accompanying staff questions about Agnes. Some of the questions asked by the paramedic about Agnes:

"So what happened today?... Okay, so the GP came today, what time did the GP come to see Agnes?... The GP put her on antibiotics? (confirming what the carer said).... Do you have her obs (vital signs)?... What other symptoms did she have?... Is she verbal?... What is her medical history?... How often does she have seizures?..."

Agnes is brought to triage and the paramedic endorsed Agnes to the admitting nurse. While they are talking the carer overheard the nurse say;

"they brought her in for a tummy ache?"

Agnes is brought to an assessment unit after triage. A nurse came to her and introduced herself to Agnes and asked her how she was, then the nurse directed her questions to the accompanying carer:

"Can she speak?... What is her baselines? (the carer clarified with the nurse what she meant by baselines)... Does she have any allergies?... Can she take her tablets orally? (the carer informs the nurse that Agnes has dysphagia)... Oh, so she can't swallow properly, what grade thickness (fluid drink thickness is graded) is she on? We have to refer her to speech and language, just in case she gets admitted... Do you know her weight?..."

What is her history?...Does she have seizures all the time? What is she normally like when she is having seizures?"

After the nurse leaves, the nurse manager arrives a few minutes later and asks the carer a few more questions and confirms some of the details. Some questions by the manager:

"How is her ADL's (activities of daily living)... Can she use the toilet on her own?...Is she always in a wheelchair?... Does she have any allergies?... (Agnes started to have a seizure) Is this her normal seizures?... Do you think she is in pain?"

One of the doctors came in to take bloods, she introduced herself to Agnes. She then directed her questions to the staff:

"Is she verbal?...What is she like normally?... What is her ADL's like?...What is she like getting her bloods done?... (doctor fails to hit a vein) Is she normally hard to get bloods from?"

The doctor went out and later came back with another doctor. While the other doctor was trying to take bloods, the other doctor is asking the carer a few more questions:

"Can she communicate, can she understand?... What is she like having a seizure?... (doctor feels Agnes's abdomen) Is her abdomen normally like this?... Do you know her weight? Can she give a stool and urine sample?... What is her baseline, like what is she like normally?... Does she have any allergies?... Do you think she is in pain?"...

Later that evening, Agnes is moved to another unit within the same A&E. It is attended by another group of nurses and doctors. The first nurse introduced himself to Agnes then directed his questions to the carer. The questions are very similar to the questions asked earlier. Another nurse came by to try and place a catheter, she asked the carer a few questions:

" Is she cooperative?... Will she let us put this (catheter) in?... Does she have any urinary problems?... (Agnes started to have a seizure) Is this how she is with her seizures? Does she have any allergies?"

Another doctors came to assess Agnes then proceeded to ask the carer about Agnes. She started to feel Agnes' abdomen and asked:

"Is her abdomen normally like this?... What is she like normally when she has a seizure?... Does she have any allergies?... What is she like when she is pain?... What is her baselines, what is she like with her ADL's?"

During the course of the evening, a senior doctor came by several times to ask about Agnes. Some of the conversation went like this:

"Is this how her seizures normally are?... How often does she have seizures before?..... Can she talk?... Does she have any allergies? Oh, wait I asked you this before (the doctor asked the same question for the third time) ... Look, I'm going to call the relatives regarding advanced protocols so I need to confirm some facts, What are her ADL's like?... Can she feed herself?... Has she always been in the wheelchair?... Can she do things herself?... Do you know the stage of her dementia?... How long has she been non-ambulatory?"

Agnes spent most of the evening in A&E, and during that time she was seen by 5 nurses, 3 junior doctor and 2 senior doctors. Agnes spent time in three locations in A&E, triage and 2 other assessment units, before being moved to the wards. The carer is not allowed to go into triage so all the transaction are in the assessment units. It is not known how many health professionals Agnes met there.

The amount of questions asked from the carer show how much information is needed by hospital staff. It also shows the reliance of hospital staff on the carer. There does not seem to be a backup if the carer is not available. The only other option if the carer is not available is calling the ID service or locate Agnes' family.

Most of the questions asked by doctors and nurses are similar. The same information but used for different tasks. Some information though appear to be more important than others. There are questions, such as allergies, that are repeated more often than others, which is understandably very important. Agnes could be given medication she is allergic to.

Information does not seem to be communicated very well within the unit. When a staff asks a particular question, another staff comes in to ask the same question. Sometimes the questions are repeated to confirm information and sometimes reconfirmed again. Other questions that are asked by hospital professionals are directed towards what the hospital professional is doing at that instance, such as when taking bloods. The questions are also short, direct questions. This is probably the nature of A&E where information is needed quickly to make a diagnosis and start treatment as soon as possible.

Remarks observed during conversations with hospital professionals are also valuable in observations. Table 3 lists some of the remarks observed while the carer was having conversations with the hospital professionals.

Table 3 Sample of observed remarks by hospital professional regarding people with ID

"it is not too bad, as long as there is a carer around". - Nurse

"not really, if they are combative, that's the problem."- Nurse

"Yeah, if they can't follow commands, it can take a while."- Doctor

"Yeah, It could be difficult if they can't communicate."- Doctor

4.2.3 Case scenario 2

John has not been himself for the last couple of days. He refuses activities that he normally enjoyed and starts spending a lot of time in his room. He started a temperature and put on antibiotics by the GP. He started refusing to eat and drink so he is brought to hospital for more investigations. He is later admitted to the male medical ward of a tertiary hospital. John has severe ID and is not verbal. He also exhibits behaviors that challenge. During the first few days of hospitalization a carer is provided from the residential home. Unfortunately the residential home had

staffing issues on several occasions during hospitalization and they could not provide a care staff every day. This is communicated verbally to the staff nurse in the ward who looked worried and said:

"Oh no, I must say this to our manager"... (The nurse left and returned after several minutes) Yeah, I don't think we are getting a special (extra staff), they'll (next day staff) have to deal with it I suppose."

As the carer is leaving, the carer stopped by the nurses' station to let them know about his challenging behaviors. The care staff verbally communicated to the hospital nurse regarding the patients challenging behaviors and how to try and prevent it, the staff nurse said "ok, thanks". After two days, care staff from the residential home is finally reinstated, it is made known to the staff that the client had pulled one of the staff nurses hair.

Although it could only be assumed, the challenging behavior might not have been communicated to other nursing staff. The nurse who received the message could have forgotten the information because the ward is busy. The information could have been written but got lost in the notes. Alternative ways of communicating important information regarding the person with ID must be established.

4.2.4 Case scenario 3

Paul has severe ID and requires full assistance with his ADL's. He has problems with swallowing so he is fed thru a tube to his stomach called a PEG. All fluids and medication are delivered through the PEG. Paul also suffers from epilepsy and takes daily medication to control his seizures. He is hospitalized at least once a year for different health problems. If Paul is admitted, he would stay in hospital for several days up to several weeks. Most of the time that he is admitted, a staff from the residential home would be allocated to stay with him during the day. From time to time though, staff will be delayed in going to hospital or there will be no one going to see him for a day or two. On one occasion when he is admitted to hospital, care staff came in the afternoon to find his morning tablets left out for him in a medicine cup.

The issue of the tablets left out for Paul could easily have been a mistake or is forgotten by Hospital staff could have been expecting workers from the residential

home that day so they left it out for them. But the worst possibility is that it is left out for Paul to take them himself. If the latter is the case then there is a strong possibility that hospital staff had no idea of Paul's capabilities. If the medication is fed to Paul it would potentially have caused choking.

4.2.5 Conclusion

The three scenarios illustrate hospital situations where people with ID are in a vulnerable position due to an acute deficit of information; information that is needed by hospital professionals to base their action or decisions. The hospital environment can be a very busy and stressful place where mistakes can easily happen. It is in these kinds of environment where people with ID are reported to receive poor quality care (MENCAP 2004).

Hospital professionals seem to have an over reliance on carers for information. Iacono & Davis (2003) explains that reliance on carers resulted from hospital professionals lack of skill and time. This situation works against the most vulnerable people in society and much needs to be done to mitigate its effects. The next section presents the results of the survey questionnaire distributed to doctors and nurses.

4.3 Questionnaire Results

4.3.1 Introduction

The administered survey questionnaire is divided into two parts. The first part is comprised of several demographic and probing questions. The second part consists of items of information for a hospital health passport. The items are ranked by respondents according to level of importance.

This section outlines the findings of the survey questionnaire administered to doctors and nurses. An overview of the response to the questionnaires will be presented first, followed by the results. The results of the questionnaire are grouped into themes that follow the outline of the research questions. The themes are; experience caring for people with Intellectual Disability (ID), difficulties and challenges caring for people with ID, hospital health passports and information technology. The questions within the themes will be presented with the corresponding responses. Tables and graphs will be used to illustrate some of the data gathered. Following the themed responses is analysis of results of the items of information (second part) of the questionnaire. The items are presented in tables regarding how important doctors and nurses view each of them.

4.3.2 Return of survey questionnaires

The original intention of the study is to survey participants from three large tertiary hospitals. Due to the reasons explained in the methods, network or chain referral sampling is employed instead to contact participants. Participants are contacted through professional and social networks. Several key contacts are targeted to be mediator to gain access to other respondents who satisfy the inclusion criteria. Coincidentally, all respondents are also from three tertiary hospitals. There are 43 questionnaires returned, 35 from nurses and 8 from doctors. This method of contacting participants have several downsides including difficulty determining how many refused to participate.

Respondents are given the choice to either fill in a paper based survey questionnaire or the equivalent online version. The online version did not have any response, all

the data came from the paper-based questionnaire. Those who were handed the questionnaire by the researcher expressed that they would rather fill in the questionnaire and return it as soon as possible. Similarly, report from the mediators suggest that most of the contacts who agreed to take part in the study returned the questionnaires on the same day. This is quite surprising since online questionnaires have grown in use and it is thought that some would at least consider taking the online survey. Although there are studies that show that people still prefer paper-based survey than online surveys (Hohwü et al. 2013) this does not explain why there is no response on the online survey.

4.3.3 Experience working with people with ID

There are four questions within this group. These questions relate to having taken care of a person with ID in the last 12 months. The time frame of 12 months is used to have a reference point for the participants.

4.3.3.1 Have you taken care of a person with Intellectual Disability in the last 12 months?

Participants who answered "no" to this question or who did not take care of people with ID, were asked to skip the next three questions (See Appendix). Twenty-eight (65.1%) of the 43 respondents have taken care of a person with ID in the last twelve months. Within the professions, 21 (60%) of the nurses and 7 (87.5%) of the doctors took care of a person with ID in the last twelve months. Figure 1 shows the distribution of nurses and doctors who have taken care of people with ID in the last 12 months.

A Chi square test is used to determine if there is a statistical significance between the two professions in relation to having taken care of a person with ID in the last 12 months. A Fisher's Exact test value from the chi square test has produced a value of (p) .226 with a confidence interval of 95%. The Fisher's Exact test value is used as one of the variables is less than 5. *"No more than 20% of the expected counts are less than 5 and all individual expected counts are 1 or greater"* (Moore 2010). This

result show that there is no statistical significance or no relationship between profession and taking care of people with ID.

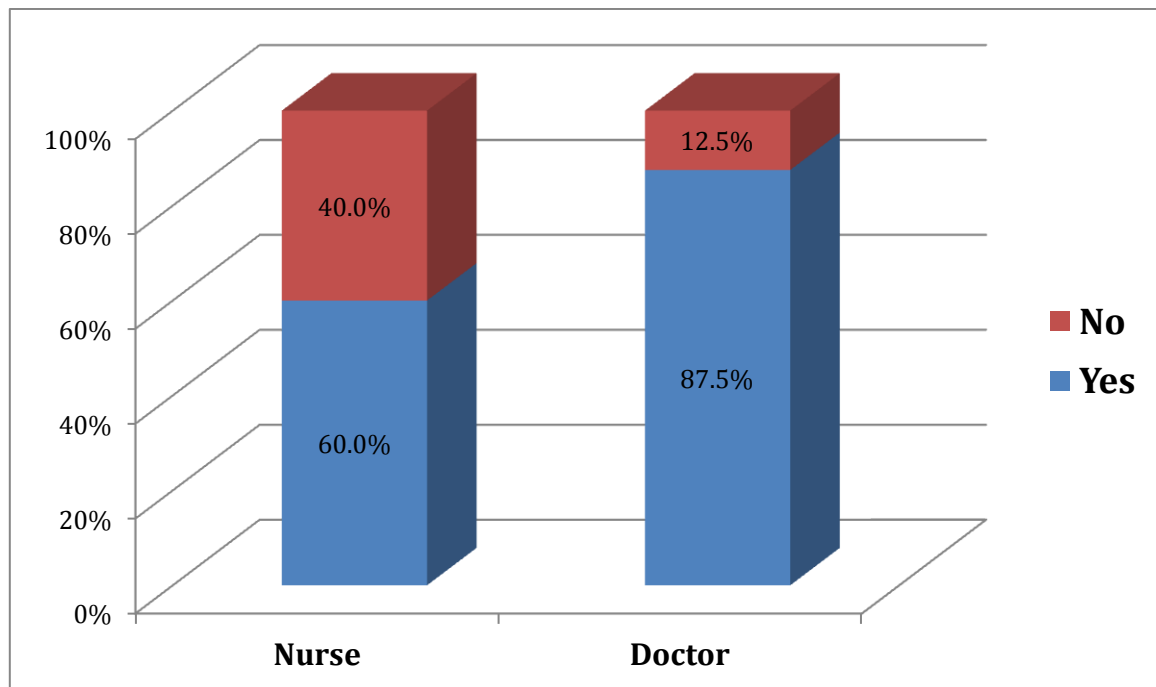


Figure 1. Experience taking care of people with ID in the last 12 months

4.3.3.2 Please estimate the number of time you took care of a person with ID in the last 12 months?

The respondents who took care of people with ID are asked to estimate the number of times they have taken care of people with ID in the last 12 months. Across both professions who took care of people with ID, the mode is 2. There are two respondents who answered this question differently. One respondent wrote down "100+" and the other respondent wrote down "almost every day". Unfortunately the answers cannot be clarified about what the respondents meant to get an accurate number. The question may have needed to be clarified to ask how many individuals with ID are did the respondents care for in the last 12 months. A person with ID may have been hospitalized for several weeks and the same person is seen "almost

every day". Both answers are placed in table 4 as 12+ (12 is the highest exact value from the respondents).

Table 4 Estimated number of times respondents took care of person with ID in the last 12 months

No. of times	No. of respondents	Percentage
1	3	11.5%
2	9	34.6%
3	3	11.5%
4	3	11.5%
5	1	3.8%
6	0	0%
7	1	3.8%
8	2	7.7%
9	0	0%
10	1	3.8%
11	0	0%
12	1	3.8%
12+	2	7.7%
Total	26	100

4.3.3.3 *Is the last person with ID you took care of accompanied by a carer or relative?*

There are 28 respondents who took care of people with ID in the last 12 months, 26 respondents answered this question. Fourteen (53.8%) said that the last person with ID they took care of are accompanied by a carer or relative. Ten (38.5%) respondents said the last person with ID they took care are not accompanied by a carer or relative. Two of the 28 respondents who took care of a person with ID did not answer. This result is illustrated in figure 2.

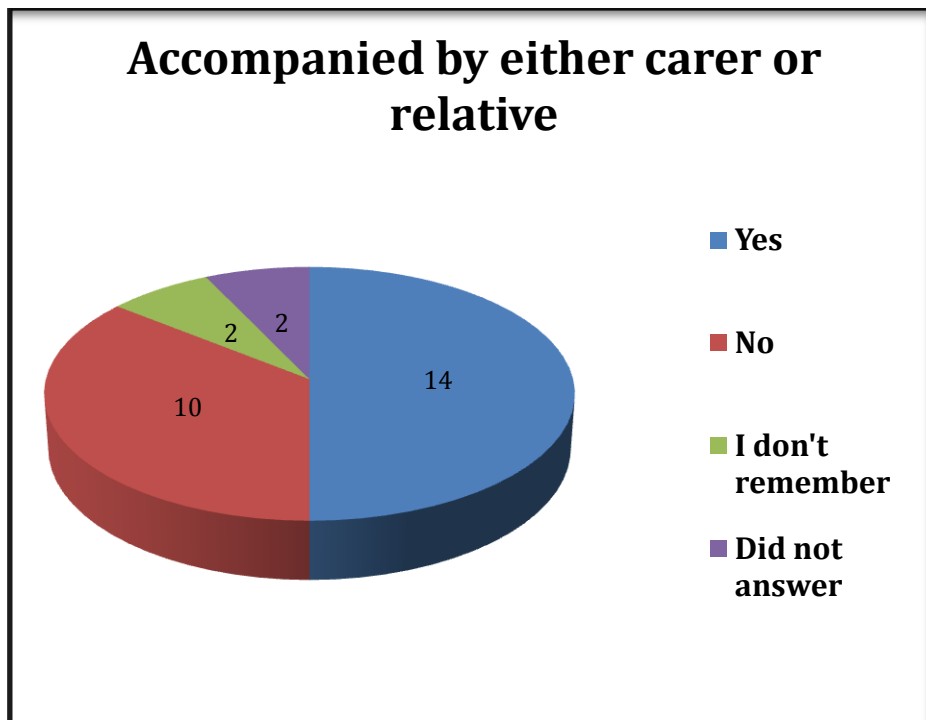


Figure 2 Shows if the last person with ID the respondent saw is accompanied by a carer or relative.

4.3.3.4 If you needed more information about the person with ID, who did you get your information from?

This question is answered by 25 respondents out of the 28 respondents who took care of a person with ID in the last 12 months. Twenty four (96%) of those who answered said that the carer is their main source if they needed more information about the person with ID. One respondent said they got their information from the person with ID.

There are three respondents who wrote other answers on the questionnaire. Two wrote down that they got their information from the care notes from the nursing home and one wrote "*from the nursing home*". The latter could have meant contacting the home through phone. It is also the case that the homes call the hospital to get updates from the hospital and information could be transferred at that point.

4.3.4 Difficulties encountered with intellectual disability

This group of statements pertain to the difficulties and challenges encountered by the respondents in taking care of a person with ID. Four statements are posed to the respondents and they are asked to rate each statement in a scale. The five point scale ranged from strongly agree to strongly disagree.

4.3.4.1 "It is difficult to care for people without ID"

Twenty-seven (62.8%) respondents moderately to strongly disagreed with this statement. Seven (16.3%) moderately to strongly agreed with this statement while 9 (20.9%) neither agreed nor disagreed. Mann Whitney U test for independence with respect to the two professions indicate that there is no statistical significance between the responses of nurses and doctors in relation to the statement. The significance value (p) is 0.407 with 95% confidence.

A cross tabulation of results show that the answers of both respondents who have and have not taken care of a person with ID in the last 12 months are both skewed towards "*disagree*" (figure 3). Mann Whitney U test for independence show that there is a relationship between the variables with a significance value (p) of .000 with 95% confidence. Descriptives show a mode of "*strongly disagree*" for those who did not experience taking care of people with ID and "*moderately disagree*" for those who have taken care of ID (table 5).

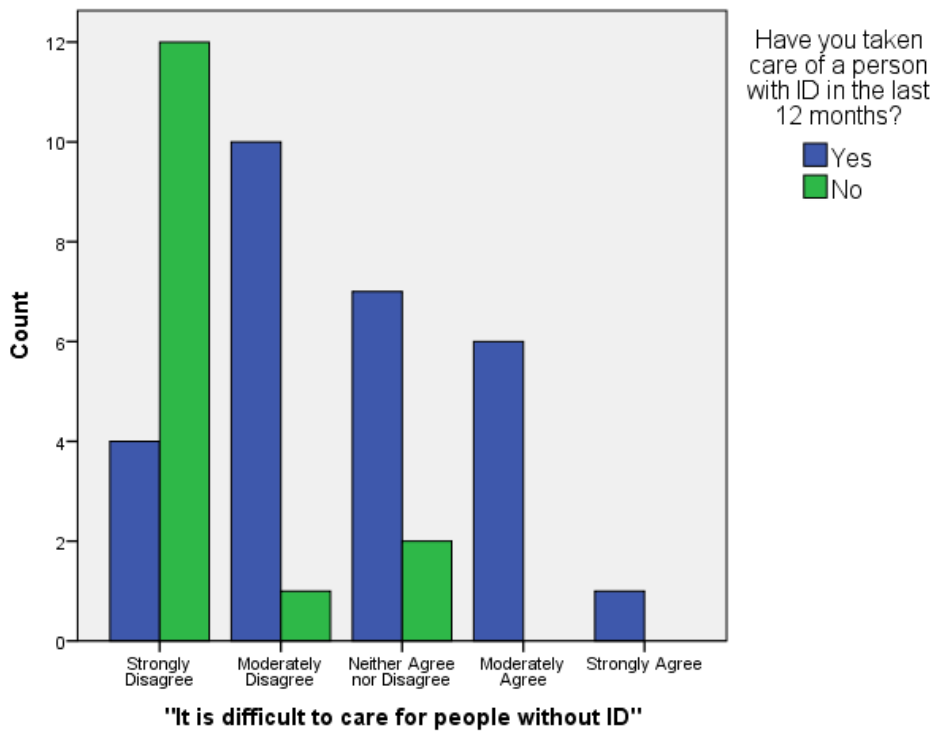


Figure 3 Extent of agreement or disagreement to the statement "It is difficult to care for people without ID" between respondents who did and did not take care of a person with ID.

Table 5 Cross tabulation of response to the statement "It is difficult to care for people without ID" and those who have and have not taken care of people with ID in the last 12 months.

Rating Scale	Taken care of person with ID	
	Yes	No
Strongly Disagree	4 (14.3%)	12 (80%)
Moderately Disagree	10 (35.7%)	1 (6.7%)
Neither Agree nor Disagree	7 (25%)	2 (13.3%)
Moderately Agree	6 (21.4%)	0
Strongly Agree	1(3.6%)	0
Total	N=28 (100%)	N=15 (100%)

4.3.4.2 "It is difficult to care for people **with ID**"

Twenty-two (51.1%) of responses moderately or strongly agreed that it is difficult to care for people with ID. Sixteen (27.3%) of respondents moderately to strongly disagreed with the statement, while 5 (11.6%) neither agreed nor disagreed. The mode is moderately agree. Mann Whitney U test for independence with respect to nurses and doctors show that there is no statistical significance between response of the two professions. The significance value (p) is 0.085 with 95% confidence. The response that appears the most is moderately agree.

A cross tabulation of results between this question and having experienced taking care of people with ID show a more pronounced outcome. Those who have experienced working with people with ID are skewed towards "*agree*" whereas those who have not are skewed towards "*disagree*"(figure 4). Mode for those who have experience taking care of people with ID is moderately agree. Mode for those who have no experience taking care of people with ID is strongly disagree (table 6). Mann Whitney U test for independence provides a significance value (p) of .004 with 95% confidence. This indicates that there is a relationship between having experienced taking care of a person with ID in the last 12 months and the perception of difficulty to take care of people with ID.

Statements 4.3.4.1 and statement 4.3.4.2 are ordered accordingly to try and prevent leading the respondent into a predictable response (see Methodology).

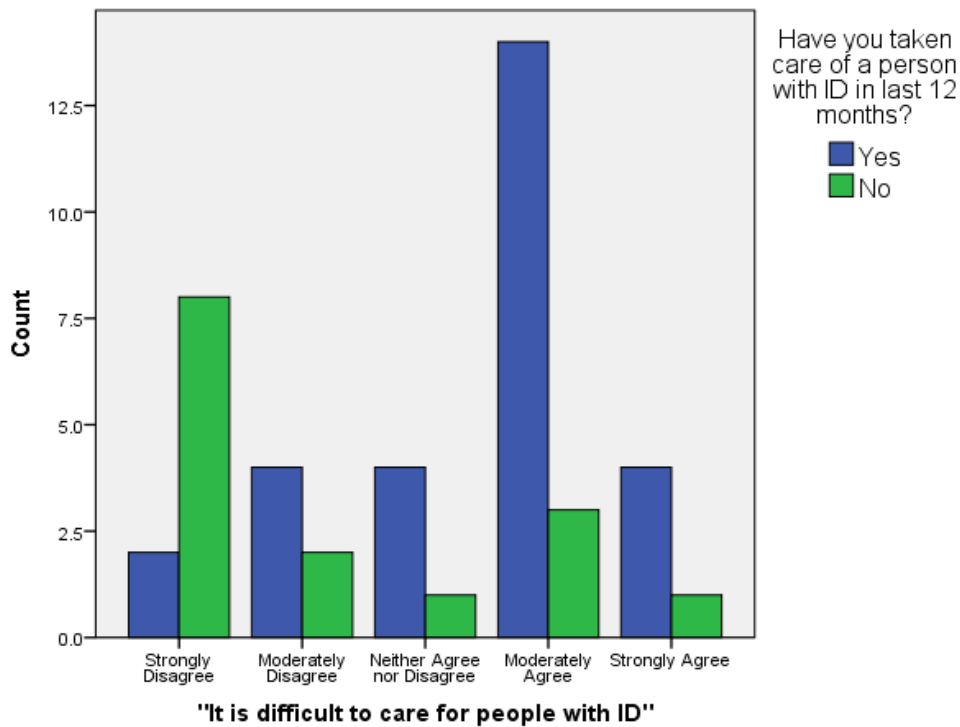


Figure 4 Extent of agreement or disagreement to the statement "It is difficult to care for people with ID" between respondents who did and did not taken care of person with ID.

Table 6 Cross tabulation of response to the statement "It is difficult to care for people with ID" and those who have and have not taken care of people with ID in the last 12 months.

Rating Scale	Taken care of person with ID	
	Yes (N=28)	No (N=15)
Strongly Disagree	2 (7.1%)	8 (53.3%)
Moderately Disagree	4 (14.3%)	2 (13.3%)
Neither Agree nor Disagree	4 (14.3%)	1 (6.7%)
Moderately Agree	14 (50%)	3 (20%)
Strongly Agree	4(14.3%)	1 (6.7%)

4.3.4.3 "I need more background information regarding the person with ID than a person without ID"

Twenty (47.7%) respondents moderately to strongly agree that they need more background information regarding the person with ID than people without ID. Fifteen (35.7%) respondents moderately to strongly disagree to the statement, while 7 (16.7%) neither agree or disagree. The most common rating for this statement is strongly agree with 13 respondents. Mann Whitney U test for independence regarding the responses and the two professions yielded a significance value (p) of 0.211 with 95% confidence. This indicates that there is no statistical significance regarding the responses of doctors and nurses in relation to the statement.

Cross tabulation with having experienced taking care of person with ID in the last 12 months shows that responses are skewed towards opposite ends (figure 5). Mode for those who have taken care of a person with ID in the last 12 months is "strongly agree" whereas those who have not is "*moderately disagree*" (table 4). Mann Whitney U test for independence produced a significance value of .011 with 95% confidence. This shows that there is a relationship between having taken care of a person with ID in the last 12 months with the perception of need for more background information for people with ID.

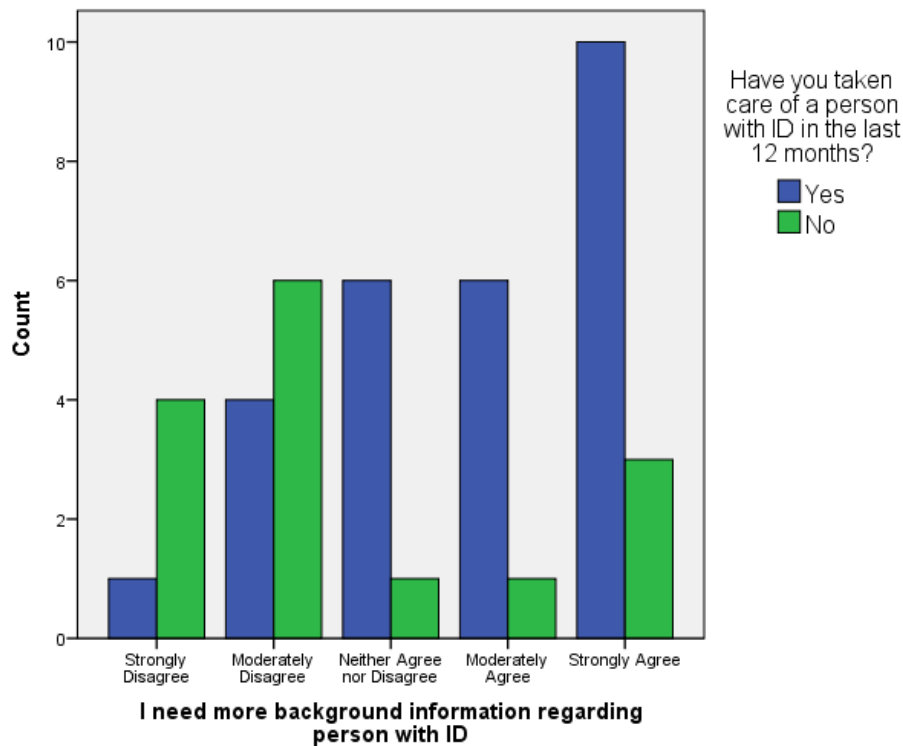


Figure 5 Extent of agreement or disagreement to the statement "I need more background information regarding person with ID" between respondents who did and did not taken care of person with ID.

Table 4. Cross tabulation of response to the statement "*I need more background information regarding a person with ID than a person without ID*" and those who have and have not taken care of people with ID in the last 12 months.

Rating Scale	"I need more background information regarding a person with ID than a person without ID"	
	Yes (N=27)	No (N=15)
Strongly Disagree	1 (3.7%)	4 (26.7%)
Moderately Disagree	4 (14.8 %)	6 (40%)
Neither Agree/ Disagree	6 (22.2%)	1 (6.7%)
Moderately Agree	6 (22.2%)	1 (6.7%)
Strongly Agree	10(37%)	3 (20%)

4.3.4.4 "I need more training to communicate with people with ID"

The mode for this statement is strongly agree with 12 (27.9%) respondents. Both moderately agree and strongly agree account for 20 (46.5%) respondents. Moderately disagree and strongly disagree account for 14 (32.5%). Nine (20.9%) responses are neither agree nor disagree. Mann Whitney U test for independence between professions provide a significance value (p) of 0.873 with 95% confidence. This indicates that there is no statistical significance between the responses of doctors and nurses in relation to the statement.

Cross tabulation of results with having taken care of people with ID in the last 12 months indicate a difference in opinion. The mode for respondents who have taken care of people with ID is "*neither agree nor disagree*" whereas the mode for people who have not taken care of people with ID is "*strongly disagree*". Figure 6 shows distribution of the results. Mann Whitney U test for independence yielded a significance value (p) of .215 at 95% confidence. This indicates that there is no relationship between respondents who have taken care of people with ID and respondents who have not to the need for more training to communicate with people with ID.

The responses are then divided between respondents who have taken care of person with ID and respondents who did not. Graphical histogram representation are provided in figure 7. Visually there appears to be a difference in the responses. The mode for those who took care of a person with ID is "*strongly agree*" whereas the respondents who did not is "*moderately disagree*".

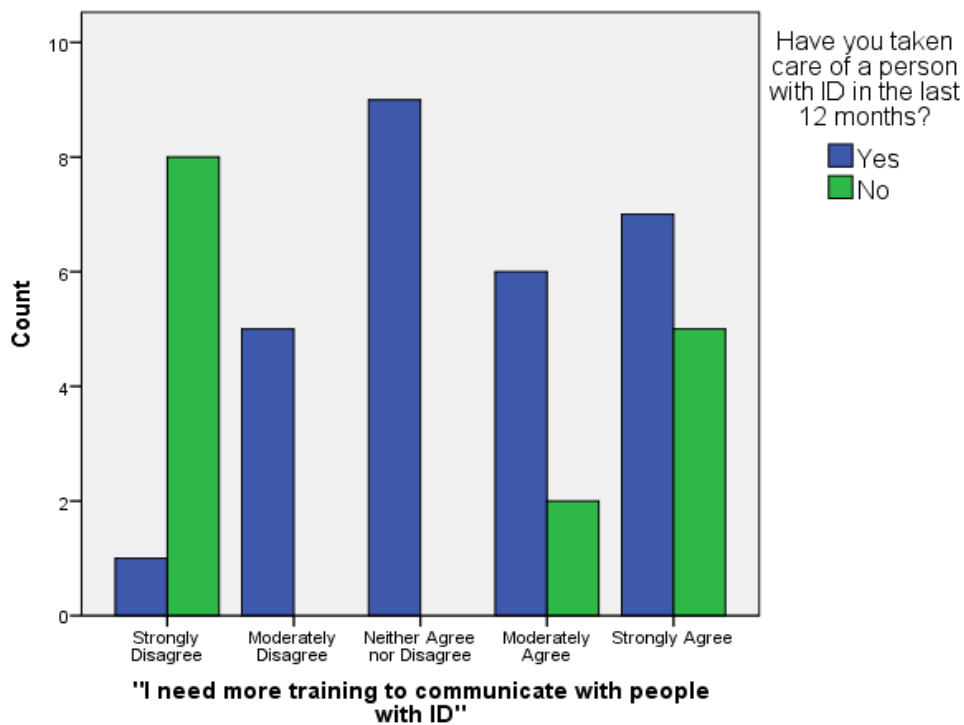


Figure 6 Extent of agreement or disagreement to the statement "I need more training to communicate with people with ID" between respondents who did and did not take care of person with ID.

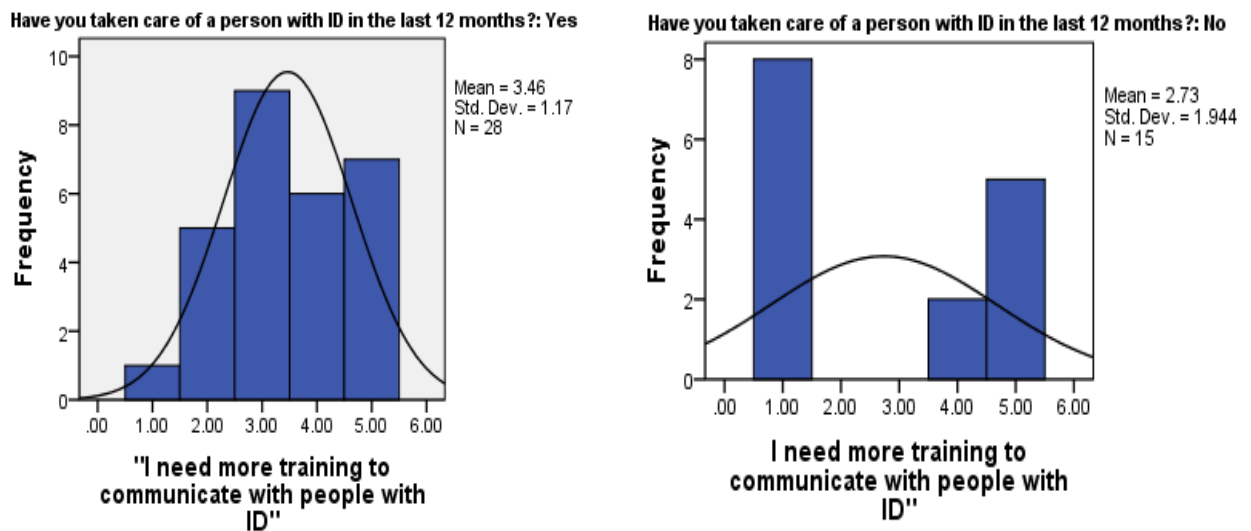


Figure 7 Histogram comparison and breakdown of extent of agreement or disagreement to the statement "I need more training to communicate with people with ID" between respondents who did and did not take care of a person with ID in the last 12 months.

4.3.5 Hospital health passports and information technology

This group of questions pertain to experience of hospital health passports and use of information technology in the hospital including responses to willingness to use information technology.

4.3.5.1 A hospital health passport is a document that contains important information regarding the person with ID. Have you encountered a hospital health passport before?

Nine (20.9%) respondents have encountered a hospital health passport for people with ID. Thirty (69.8%) respondents have not encountered a hospital health passport for people with ID. Four (9.3%) respondents do not remember encountering a hospital health passport for people with ID (figure 8).

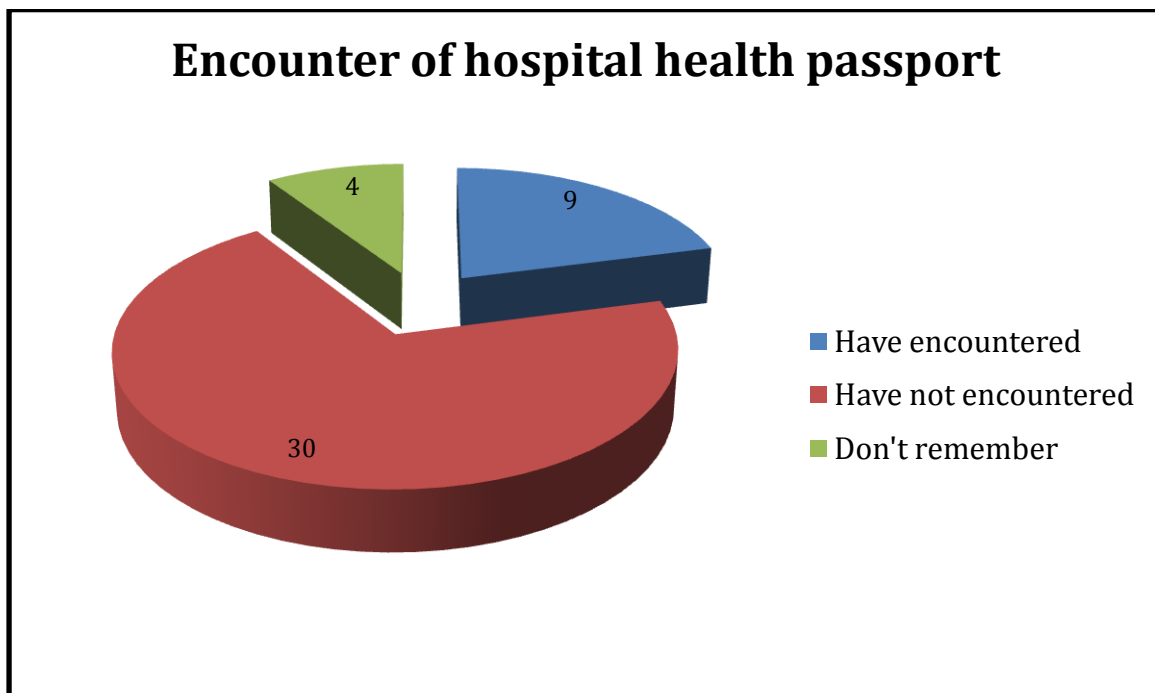


Figure 8 Number of respondents who have encountered a hospital health passport for people with ID

4.3.5.2 Use of IT in the hospital

With regard to use of information technology in the hospital, three questions are asked from the respondents. The first question asked the respondents if there is a hospital information system in the hospital. There are 17 (40.5%) "yes" responses to 16 (38.1%) "no" responses. Nine (21.4%) responded that they are not sure if there is a hospital information system in the hospital. Within the professions, 35.3% of nurses answered "yes" while 62.5% of doctors answered "yes."

The second question asked if the respondents would welcome a situation where the information in a hospital health passport is available from a secure database. Thirty-nine (90.7%) respondents would welcome the situation. One (2.3%) respondent answered no and 3 (6.9%) are not sure.

The third question asks respondents if they are prepared to update the database if they knew how. Thirty-four (79%) respondents said they prepared to update, 5 (11%) are not ready to update and 4 (9%) of respondents are not sure. Table 7 lists the results to the three questions.

Table 7 Three questions posed to doctors and nurses regarding hospital health passports and IT

	N	Yes	No	Not Sure
Is there a Hospital Information System in your hospital?	42	40.5%	38.1%	21.4%
Would you welcome a situation where the information in a hospital health passport is available from a secure computer database?	43	90.7%	2.3%	7%
Would you be prepared to update such database if you knew how?	43	79.1%	11.6%	9.3%

4.3.6 Other demographics

4.3.6.1 Wards

The respondents are asked which ward they normally worked in. The table below show the declared wards from the survey. Initially it is proposed to gather data from four wards namely; A&E, outpatients, medical and surgical wards. All except outpatients are represented in the study. Two of the responses need clarification as one responded wrote down "all" wards and the other wrote down "general" (see table8).

Table 8 The wards where respondents normally worked.

		Frequency	Percent
Wards	A and E	4	9.3%
	All	1	2.3%
	Dialysis	1	2.3%
	Gastro	1	2.3%
	General	1	2.3%
	Med-Surge	9	20.9%
	Medical	5	11.6%
	Orthopaedic	1	2.3%
	Private	1	2.3%
	Respiratory	1	2.3%
	Rheumatology	1	2.3%
	Surgical	13	30.2%
	Total	39	90.7%
Missing		4	9.3%
Total		43	100%

4.3.6.2 Length of service

Respondents are asked how long they have worked in the hospital. The questionnaire allowed for 5 bands of work experience. Table 9 shows the responses to the questionnaire. After data are analyzed, some of the data are found to be too low for analysis. The length of work experience is grouped into two groups instead of the original 5. The first group is for less than four years and the second group is for more than four years experience. There are 29 (67.4%) respondents with more than four years work experience and 13 (30.2%) respondents with less than four years experience (see table 7a). One respondent did not answer the question.

Mann Whitney U test for independence is used to determine if there is a relationship between the length of hospital experience and the four statements in difficulties section. Analysis showed that there is no statistical significance of having less than four years experience or having more than four years experience to; the perception of difficulty to take care of people with ID, the need for more background information regarding a person with ID and the need for more training to communicate with a person with ID.

Table 9 Original response to length of work experience

Length of work experience	N=42	%
More than 4 years	29	69%
3-4 years	1	2.4%
2-3 years	1	2.4%
1-2 years	3	7.1%
Less than 1 year	8	19%

Table 10 Recalculated length of work experience

Length of work experience	N=42	%
More than 4 years	29	69%
Less than 4 years	13	31%

4.3.6.3 Advanced Nurse Practitioner

This question asked if the respondents work along with an Advanced Nurse Practitioner (ANP). Seven or 16.3% of respondents answered that they did work along with an Advanced Nurse Practitioner. Thirty-five or 81.4% of respondents do not work along with an Advanced Nurse Practitioner. The role of an (ANP) in promoting safer healthcare is documented in the literature (O'Grady 2008). Although ANP post are slowly being introduced within other areas of healthcare, there does not appear to be as much progress in the Intellectual Disability sector.

4.3.7 Items of Information for Hospital Health Passport

The second part of the questionnaire required the respondents to rate items of information for the hospital passport. There are 42 items of information, and respondents are asked to rate each item in a five point scale, from very low importance (1) to very high importance (5). The items of information are grouped into three headings; Identifying Information; Health Information; Personal Information.

Descriptive statistics show that for both profession, all 42 (100%) items of information, the value that appears the most is very high importance. Median for 34 (81%) items is very high importance, 6 (14.3%) items is high importance, 2 (4.7%) items is moderate importance.

Mann Whitney U test for independence is used to determine a relationship between profession and the individual items of information. Overall, 27 of the items did not show statistical significance while 15 items show statistical significance (table 11). Out of the 15 items that show significance, 4 items show a difference of opinion at opposite ends of the scale (tables 12). The other 11 items show a difference of opinion at the moderate to very high end of the scale (table 13).

Table 11 Items of information that did not show significance

Items of Information	Significance Value (p)	Nurse		Doctor	
		N	Mean	N	Mean
Name	.640	32	4.9688	7	5.0000
Date of birth	.406	32	4.8750	7	5.0000
Address	.554	32	4.1250	6	3.8333
Language Spoken	.491	31	4.6129	6	4.8333
Next of Kin	.702	32	4.9063	7	5.0000
Contact Details of Next of Kin	.949	32	4.8438	6	4.8571
Name of Main Carer	.784	32	4.7188	7	4.7143
GP Details	.769	32	4.3750	7	4.2857
Legal Representative	.089	32	3.6563	7	2.5714
Current Medication	1.000	34	5.0000	7	5.0000
Allergies	1.000	34	5.0000	7	5.0000
Immunisations	.301	34	4.4118	7	4.0000
Swallowing Difficulties	.760	34	4.8824	7	4.7143
Pain	.063	34	4.8235	7	5.0000
How the Person Takes Medication	.151	34	4.9118	7	4.7143
Family history	.277	34	4.1176	7	3.7143
Other services involved	.703	34	4.3824	7	4.2857
Other medical problems	.261	34	4.5588	7	4.8571
Women's health	.119	33	4.3636	7	3.7143
Method of communication	.783	33	4.7273	7	4.5714
Signs of anxiety	.063	34	4.6176	7	4.1429
Personal Care	.055	34	4.7353	7	4.0000
Feeding	.101	34	4.5588	7	4.0000
Safety concerns	.071	34	4.6471	6	4.0000
Person who completed data set	.871	34	4.1471	6	4.5000
Level of ID	.075	34	4.7059	7	4.0000
Ability to give consent	.977	34	4.8529	7	5.0000

Table 12 Items of information that show significance and show opposing polarity.

Items of Information	Significance Value (p)	Nurse		Doctor	
		N	Mean	N	Mean
Medical card number	.028	31	3.4516	6	1.8333
Health Insurance Details	.002	32	3.4375	6	1.3333
Likes	.001	34	4.6471	6	2.8333
Dislikes	.002	34	4.6176	6	2.8333

Table 13 Items of information that show significance and show similar polarity

Items of Information	Significance Value (p)	Nurse		Doctor	
		N	Mean	N	Mean
Phone Number	.052	32	4.3438	6	3.1667
Types Of Accommodation/Service	.044	31	4.1290	6	4.0000
Medical History and Treatment Plan	.028	34	5.0000	7	4.8571
Sensory Deficits	.007	34	4.7059	7	4.0000
How the Person Tolerates Medical Intervention	.000	34	4.8529	7	3.8571
Advance directives	.029	34	4.7353	7	3.8571
Men's health	.038	34	4.4118	7	3.2857
Support for challenging behaviour	.021	34	4.7059	7	4.1429
How the person mobilizes	.012	33	4.8485	7	4.2857
Toileting	.017	34	4.6765	7	4.0000
Sleep Pattern	.014	33	4.3939	7	3.4286

4.3.8 Additional Items

A section at the end of the questionnaire is provided for the respondents for information they feel should be included in the hospital passport (table 14). Three respondents left 8 items in the questionnaire. All three respondents who left items are nurses.

Table 14 Additional items proposed by respondents

Items of Information	Level of Importance
Blood group	High importance
History of previous infections	Very high importance
History of aggression	Very high importance
History of agitation	Very high importance
Name of special toys or comfort things	Moderate importance
Urinary continence	Very high importance
Bowel continence	Very high importance
ADL/routine	Very high importance

4.3.9 Conclusion

This section outlined the results of the survey questionnaire. There were 43 questionnaires collected from 35 nurses and 8 doctors. The questions are grouped thematically according to themes that follow the outline of the research questions to support interrogation of the results. Statistical analyses of the results are presented with tables and graphical illustrations to compliment the findings. The following section will discuss the results in relation to the research questions and aim of this study.

Chapter 5 Discussion

5.1 Introduction

This chapter provides a discussion of the findings presented in the results chapter. The main points raised will be examined with a view to resolving the research questions. The case scenarios and the results of the survey questionnaire are assimilated to reach conclusions regarding the research questions.

The main aim of this research, is to determine the minimum data required by clinicians for a standard hospital health passport. To achieve the main aim, several research questions are set to guide the research. The research questions are discussed individually in relation to the findings and results from the study. The research questions are presented below:

- Do doctors and nurses find taking care of people with ID more difficult compared to people without ID?
- Do doctors and nurses require more background information to care for people with ID?
- What are the implications of a standard hospital passport in relation to future Hospital Information Systems for people with ID?
- Is there a difference between the information required by doctors and nurses for the hospital health passport for people with ID.

5.2 Do doctors and nurses find taking care of people with ID more difficult than caring for people without ID?

The review of literature has shown that the health needs of people with ID are complex and they are more likely to end up in hospital than people in the general population. Unfortunately for people with ID, mainstream hospital professionals lack training or formal education in taking care of them (DHSSPS 2005). Even with a lack of formal training or experience, doctors and nurses are still expected to take care of

people with ID. It could be argued that doctors and nurses may find it more difficult to take care of people with ID than the general population. In the study, doctors and nurses are asked if they agree or disagree with the statement "*it is difficult to take care people with ID than people without ID*". From the results of the questionnaire, 66.6% of respondents who do not have experience taking care of people with ID, feel that it is not difficult to take care of people with ID. Only 26.7% of those who do not have experience agree with the statement. This result is contrast to the findings of people who have experience taking care of people with ID. From the results of the questionnaire, 64.3% of respondents who have experience taking care of people with ID feel that it is difficult to care for them. While 21.4% of respondents who have experience feel that it is not difficult to care for them.

The findings suggest that majority of doctors and nurses who do not have experience caring for people with ID may not appreciate the challenges of ID. Doctors and nurses who have no experience may have preconceived ideas about people with ID which are different from actual situations. This can be associated with the term 'diagnostic overshadowing' where hospital professionals make decisions based on wrong assumptions regarding ID.

Another impact on staff from lack of experience is on confidence with dealing with ID. A focus group comprised of Accident and Emergency nurses, expressed fear and vulnerability as care providers in caring for people with ID, mainly due to lack of previous experience or education (McConkey and Truesdale (Glaysher 2009). The study also found that there is lower confidence of staff towards ID than other forms of disability.

The case scenarios in the results chapter offer a glimpse of the challenges doctors and nurses face when taking care of people with ID. The scenarios and the results of the questionnaire appear to validate the conclusion that it is more difficult to take care of people with ID than the general population. Deficits in information, behaviour problems, lack of training and education are just few of the difficulties encountered by hospital professionals. The carer supporting the person with ID in hospital is invaluable in overcoming these challenges. The scenarios and the literature suggest that there is over reliance on carers and this becomes apparent when the carer is not available. Comments from hospital professionals such as "*it is not too bad, as long*

as there is a carer around" and *"it could be difficult if they can't communicate"* strengthen the findings and confirms the hypothesis that doctors and nurses do find it more difficult to take care of people with ID.

5.3 Do doctors and nurses require more background information to care for people with ID?

Many people with ID have problems associated with communication. The review of literature explains that people with ID can express themselves in atypical ways that hospital professionals might not be able to understand. The ability of people with ID to communicate can vary from one individual to another, from those who can speak to having no speech at all. Doctors and nurses may not have the necessary tools to communicate properly with a person with ID. Even staff who work with people with ID have difficulty gauging their ability to communicate. A study by McConkey et al. (1999) observed that ID staff's perception of the clients ability to communicate overestimated the clients actual ability to communicate. If ID staff finds it difficult to estimate a person with ID's communication ability, a hospital professional who have no experience caring for them will probably find it even more difficult.

The communication of information is important and any breakdown in the communication process leads to poor outcomes in the hospital (Kripalani et al. 2007). Information or the lack of it can mislead or delay diagnosis and eventually treatment. It can be hypothesized that doctors and nurses need more information to care for people with ID than the general population. Similar to the previous research question, experience working with ID is a factor again in discussing this hypothesis. From the results of the questionnaire, 66.7% of respondents who have no experience taking care of people with ID feel that they do not need more background information to care for them. Compared to 60% of doctors and nurses who have had experience taking care of people with ID feel that they need more background information to care for them. It could be argued that the viewpoint has changed for doctors and nurses who have experience taking care of people with ID.

A related finding from the questionnaire is the perception of the need for more training to communicate with people with ID. From the results of the questionnaire, 53.3% of doctors and nurses who did not have experience taking care of people with

ID, do not feel the need for more training to communicate with people with ID. For respondents who have experience taking care of people with ID, only 21.5% of respondents do not feel the need for more training. It could be assumed that after experiencing caring for people with ID that the need for more training to communicate with them becomes appreciated.

The first case scenario from the results exhibits the information deficits in assessing a person with ID in the A&E. Decisions about treatment and prognosis of patients in hospitals are usually based on the information gathered by the clinician. In the absence of a hospital health passport, the only reliable source is the carer. Without the carer it would be very challenging for the hospital staff. Trying to establish a diagnosis for people with ID will take longer without reliable information. The paper by Morad & Merrick (2005) indicates that the assessment process could take as much as four times longer for people with ID than the general population.

Information and how it is communicated are both important factors in delivering healthcare services to all patients. It could be argued that it is more so in people with ID. A phenomenological study by Cumella & Martin (2004) identified that lack of information from primary and specialist care staff impeded effective care for people with ID. The second case scenario is an example of a breakdown in communication where the presence of a hospital health passport could have been useful. Hospital professionals must have contingencies if communication do breakdown to at least decrease their over reliance on carers.

5.4 What are the implications of a standard hospital health passport in relation to future Hospital Information Systems (HIS) for people with ID?

From the review of literature, government and voluntary ID organizations are advocating the use of hospital health passports for people with ID. It could be assumed that the use of hospital health passports among people with ID will eventually grow. This could improve outcomes and limit the risk people with ID are exposed to when they enter the hospital.

The number of people with ID who use hospital passports are not known. Nor is there any data regarding extent of use of passports from organizations that cater for

people with ID. From the findings in the study, around 20% of respondents have encountered a hospital health passport from people with ID. Although this is not an indication of the extent of use of hospital passports, we could generalize that there is still many people with ID who do not use a hospital passport.

The standardization of datasets, such as the recently published National Standard for Patient Discharge Summary (HIQA 2013), is a key component for future healthcare IT systems. There are still many barriers for IT to be able to deliver a better service than what it is offering now such as fragmentation of services and lack of standardization of data. If for example, the information in a hospital health passport is standardized, there is a possibility in the future that passports can be transferred electronically.

The survey shows that an overwhelming majority of clinicians (90.7%) welcome an electronic hospital passports to support care for people with ID. There are 80% of the respondents who are also willing to update the information in an electronic hospital health passport. These are all encouraging results and it could be concluded that there is growing acceptance towards IT among doctors and nurses. Information technology will eventually change the landscape of healthcare, as it did other industries, and clinicians will have to be prepared to exploit the benefits of it.

With regard to the use of IT in the hospital, respondents are asked if they have a hospital information system (HIS). From the results of the study, less than half of the respondents (40.5%) said they have a hospital information system. Around the same amount (38.1%) said they didn't have any while 21.4% are not sure. All the respondents are known to come from three tertiary hospitals who are known to have a hospital information system. As per profession, 35.3% of nurses knew they had a HIS, whereas 62.5% of doctors knew they had a HIS. This discrepancy could be related to doctors moving around the hospital more than nurses who spend most of the time in the ward. IT integration in the wards are still low, and most transactions are still paper based.

People with ID will benefit from a standard hospital health passport. It will not only prevent the proliferation of passports but also ensure the right information is collected and delivered to clinicians. If the standard hospital health passport can

transferred electronically, this will enable faster communication between IT systems of primary providers and hospital information system.

5.5 Is there a difference between the information required by doctors and nurses for the hospital health passport for people with ID?

Items of information aggregated from published hospital health passports from national and international bodies are presented to hospital doctors and nurses. Each item are rated by the respondents to find out if there is a difference between the requirements of both profession.

There are 27 items do not show a relationship between the responses of doctors and nurses. Eleven (11) items of information show that there is a difference in opinion but all 11 are skewed similarly to moderate to high importance. The remaining 4 items show a polarizing difference. The items are medical card number, health insurance details, what the person likes, what the person dislikes (table 12). The 4 items are ranked with higher importance by nurses but doctors ranked them at the lower importance.

Although doctors and nurses are both hospital professionals there are fundamental differences in their professional roles (Oberle & Hughes 2001). A study by Grundstem-Amado (1992) found that nurses placed greater emphasis on patient dignity, comfort and wishes while doctors on patients' rights, disease and its cure. These differences are reflected in the 4 items with polarizing results. The first two items, medical card number and health insurance details are important to nurses most especially for discharge planning. The medical card is important for example when liaising with the social worker such as when a patient is discharged with bandages, dressings or antibiotics that are covered by the medical card. Health insurance details are also important in discharges such as liaising with VHI homecare in continuing care at home. Knowing these information in advance saves time for the nurse as they can anticipate problems and solutions on discharge. The other two items, "*things I like*" and "*things I don't like*" also reflect the emphasis by nurses on patients comfort and wishes. Information in these items will offer shortcuts to building rapport with the patient. It will also benefit nurses greatly in promoting person centered care.

All 42 items are ranked by nurses from moderate to high importance, while doctors rank 38 with moderate to high importance. It can be argued that 90.5% are ranked similarly as important by doctors and nurses. The first case scenario from the results chapter shows a similar situation where the nurses and doctors asked the carer comparable types of information. This shows that although there are fundamental differences in the roles of nurses and doctors, their informational requirements are largely similar. They use mostly the same information to fulfill different functions and roles. The similarity of requirements justifies use of a single passport.

Additional items identified by the respondents can be collated into the list of item items of information. Some of the items identified can be classified with the items identified from the passports such as activities of daily living (ADL's) and continence.

5.6 Conclusion

Interpretation of the findings has shown that interactions between hospital professionals and people with ID are complex. But it also has shown opportunities where the quality of care can be improved. The introduction of competent staff who have the necessary experience in dealing with people with ID and the formulation of a standard hospital health passport are just few of the steps that can be taken to improve the quality of care delivered to people with ID.

Chapter 6 Conclusions

6.1 Introduction

The experience working with people with ID and the reliance of hospital staff to carers both have the potential to negatively or positively affect the quality of hospital care received by people with ID. Recommendations, such as addition of competent staff and use of a standard hospital health passport are offered to mitigate the negative effects of both outcomes. The importance of the items of information for a standard hospital health passport are explained. Limitations of the study follows. Area for future work is identified then the study is finally concluded.

6.2 Experience of working with people with ID

Experience in caring for people with ID has a major influence on the findings of this study. Doctors and nurses who have not had the opportunity to care for people with ID may not understand the challenges associated with taking care of them. The lack of knowledge or experience of ID is one of the major challenges that face hospital staff regarding ID (Hogg 2001). Other challenges identified, by (Glaysher 2009), faced by hospital professionals when they take care of people with ID are listed in table 15.

Table 15 Challenges faced by hospital professionals when taking care of people with ID (Glaysher 2009).

-
- difficulty with communication
 - time pressures
 - accessing specialist skills
 - involving patients
 - dealing with stereotypes
 - over-reliance on carers
 - difficulties in checking the patient has understood

The National Emergency Medicine Program report of Ireland (HSE 2012) have explored the use of hospital health passports for people with ID. The report considers the passport to hold enough detail not only to improve the safety and quality of care but make the person with ID feel safe and understood. The National Emergency Medicine Program report also recommends the addition of competent staff to care for people with ID. The report further requires that competent staff should have specific educational preparation listed in table 16. The educational preparations in table 16 answers the challenges identified by Glaysher in table 15.

Table 16 Specific educational preparation for competent staff (HSE 2012)

- the need to understand what Intellectual Disability is;
- the need to understand potential associated physical and behavioural problems;
- the need to understand what specific support patients require;
- exploration of effective communication methods for this group;
- understanding why and how to tailor assessment for these patients and have relevant tools available;
- awareness of who to contact for further information/advice/support;
- ensuring they are up to date on relevant legislation in relation to rights of person with ID.

6.3 Reliance on carers

More than half the time, it is reported in the survey questionnaire that the last person with ID taken care of is accompanied by a carer or family member. The carer accompanying the person with ID are also the primary resource for information for doctors and nurse. The case scenarios from the results stresses the importance of carers for people with ID in the hospital. This is a worrying situation which is complicated by lack of knowledge and confidence by hospital professionals in taking

care of people with ID. Situations where the carer are unable to attend means that the hospital professionals are thrust into an undesirable position.

Recommendations such as those by the National Emergency Report for staff competency will alleviate the reliance on carers by hospital staff. The use of a standard hospital health passport will also go a long way in ensuring hospital staff have an accessible format for comprehensive information regarding the person with ID. A standard hospital health passport will help ensure that issues arising from lack of knowledge or decisions based on wrong assumptions are limited. The information contained in a standard hospital health passport has the potential to improve the hospital experience of a person with ID in all the stages figure9 of hospital care.



Figure 9 Stages of patient flow in the hospital where a standard hospital health passport can be utilized

6.4 Items of information for a standard hospital passport

It is established in the literature that people with ID will benefit from using a hospital health passport. Unfortunately there is still no standard data set for a hospital health passport. This has led to several passports available in Ireland today. The content of each hospital passport varies but fortunately the main aim of each is the same. It is to support the person with ID to demand what everybody else expects or receives from hospital care.

The case scenarios confirms that healthcare professionals need more information from people with ID. It also shows the need for alternative sources of information if the carer is not available. The results of the questionnaire provides a list of information, compiled from other hospital health passports, that can be included in a

standard hospital passport. Although there are some differences in the requirements of doctors and nurses (see table 12,13), the discussions explain that they do not necessitate having separate documents. The items of information can be a starting point in creating a standard hospital health passport. One that will represent people with ID, not just as a disability but as a person.

Similarities with the information contained in other data sets can exploit the potential data exchange or consolidation within a hospital or patient record. Demographic information such as name, date of birth, address or even important medical information such as allergies and medical history can feed into a standard discharge summary thereby increasing the accuracy and speed of the discharge process. This could also work in reverse where information from other data sets can feed into a standard hospital health passport.

The National Standard for Patient Discharge Summary Information (HIQA 2013) addresses deficits in information between a hospital and primary care. A standard hospital health passport addresses similar informational deficits for people with ID entering the hospital. The use of both data sets have implications for patient safety and continuity of care. The information from the national standard for discharge bears resemblance to the proposed content of a standard hospital health passport for people with ID. The national standard for discharge is divided into familiar subsections from patient details, primary care professional details, admission and discharge details, clinical narratives, medication details, future management and the details of the person completing the summary. A standard hospital health passport can also be fashioned similarly, but it differs from national patient discharge in that it not only contains medical and social information but also other information that promotes equality, respect and dignity for the person with ID. Information such as likes and dislikes that aim to provide a comprehensive understanding to support those who provide hospital care to people with ID.

The study is an important first step in establishing the pieces of information that can be added in a standard hospital health passport. HIQA (2013) stated that the scope of a standard data set should be limited to include requirements which are common across a majority of specialties. A wider debate is also needed to include not just

doctors and nurses, but other clinicians involved in the person with ID's care, managers of health services and more importantly, people with ID and their carers.

6.5 Limitations of the study

This section discusses several issues in relation to rigor and approaches taken to limit the impact on results and enhance the quality of the study. In areas of social research, credibility, transferability, dependability and conformability are the methods to gauge trustworthiness in qualitative studies (Guba & Lincoln 1982). Since this study uses a mixed-method approach, Mays & Pope's (1995) strategy structure covering sampling, reliability and validity is adopted.

6.5.1 Sampling

There are two major issues in sampling identified. First, the study would have benefited from a larger sample size. This would likely ensure a representative distribution of the population to whom results will have been generalized. It would probably help in reinforcing or contradicting the findings of the study. In the some cases, some of the results are too small for statistical tests. While some sample size are low, respondents did range in age, experience, expertise and profession.

The second limitation is the selection of participants. Purposive and snowball sampling is the term used in the methodology to describe the selection of participants. This method is considered as not random which can introduce bias in the study. Although time is also a factor in this study which contributed to both limitations, the decision to use the method is not made purely for convenience. The study participants, doctors and nurses, are all working in a tertiary hospital who either had experience or had the potential to care for people with ID. All of these perspectives proved to be very valuable in the study. This could be considered as "*expert sampling*." It involves recruiting respondents who demonstrate experience and expertise in some area (Trochim 2006). Future studies that supports a larger sample size and random selection of participants may yield a higher acuity of results.

6.5.2 Reliability

Reliability is a very important concept where other researchers are able to generalize similar conclusions by following similar procedures. It is the extent to which an experiment, test, or any measuring procedure yields the same result on repeated trials (Colorado State University 2014). Even with the time constraints and issues of access discussed in the methodology, this study strived to account for bias and mitigate factors that affect findings. This study also tried to produce unambiguously the interpretation of data. This way another researcher may will arrive at similar generalizations.

6.6 Future work

Arising from the study, besides conducting larger similar studies, the issue that some staff do not appear to be aware that they have an information system could have the potential for future research study. The reason for lack of awareness could be genuine or they simply did not understand the terminology.

6.7 Conclusion

People with ID are increasingly using hospital health passports to communicate vital information to overcome barriers they face when they enter the hospital. Communication problems, lack of skills of hospital professionals and the over reliance on carers are just a few of them. It is critical for people with ID that the hospital health passport contains the essential data required by hospital professionals.

This study, first and foremost, is an exploration of a minimum data set for a standard hospital health passport. Larger studies that involve other health professionals may provide stronger conclusions, but it was established in the study that from the identified 42 items of hospital health passport information, the majority of information was found to be important by doctors and nurses. This is an important step in standardizing the content of hospital health passports and it is critical that further steps are taken to progress standardization of hospital health passports.

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Appendix A Questionnaire

Dear Sir/Madam,

May I invite you to participate in a research that I am conducting in fulfilment of the requirements for Masters in Health Informatics. The purpose of this research study is to engage with clinicians and identify minimum data required for hospital health passports. The hospital health passport is a document used by people with Intellectual Disability to communicate important information when they move from their residential area to an acute hospital setting such as the Accident and Emergency. A standard hospital health passport will allow collection of comprehensive and consistent data that can be analysed by clinicians to improve the quality of care they provide. I also want to examine the information required by nurses and compare them with doctors.

Can you please either answer the attached questionnaire and mail it back to me in the self-addressed, postage-paid envelope or alternatively go to <http://hospitalhealthpassport.limequery.com/> for the equivalent online questionnaire. Please fill up only one. The survey should take only 10-15 minutes of your time. Your answers are anonymous so please **DO NOT** write your name. The answers will be kept confidential and only the group results will be documented. This research is voluntary and you do not have to answer any questions you are not comfortable answering. A space for comments is provided at the end for any remarks you wish to include. The return of a completed survey will indicate your consent to participate in the study.

The results of this survey will be presented to the School of Computer Science and Statistics in Trinity College Dublin. Ethical approval was sought from the school ethical committee. If you have any questions or concerns please contact me at quintinj@tcd.ie. Thank you very much and I hope to receive a completed survey from you soon.

Regards and best wishes,

James Quintin

“ Each question is optional. Please feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised.”

PART 1

Information for clinicians taking care of people with ID in an acute hospital setting.

1	Have you taken care of a person with Intellectual Disability (ID) in the last 12 months? <input type="radio"/> Yes <input type="radio"/> No (if no, please proceed to 5) <input type="radio"/> I don't remember																														
2	Please estimate the number of times you took care of a person with ID in the last 12 months? _____																														
3	Was the last person with ID you took cared of accompanied by a carer or relative? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> I don't remember																														
4	If you needed more information about the person with ID, who did you get your information from? <input type="radio"/> Carer <input type="radio"/> Person with ID <input type="radio"/> I don't remember																														
5	<table border="0"> <thead> <tr> <th>To what extent do you agree or disagree with the following statements</th> <th>Strongly Agree</th> <th>Moderately Agree</th> <th>Neither Agree nor disagree</th> <th>Moderately Disagree</th> <th>Strongly Disagree</th> </tr> </thead> <tbody> <tr> <td>a. "It is difficult to care for people without ID."</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>b. "It is difficult to care for people with ID ."</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>c. "I need more background information regarding the person with ID than a person without ID."</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>d. "I need more training to communicate with people with ID. "</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> </tbody> </table>	To what extent do you agree or disagree with the following statements	Strongly Agree	Moderately Agree	Neither Agree nor disagree	Moderately Disagree	Strongly Disagree	a. "It is difficult to care for people without ID. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	b. "It is difficult to care for people with ID . "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	c. "I need more background information regarding the person with ID than a person without ID. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	d. "I need more training to communicate with people with ID. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To what extent do you agree or disagree with the following statements	Strongly Agree	Moderately Agree	Neither Agree nor disagree	Moderately Disagree	Strongly Disagree																										
a. "It is difficult to care for people without ID. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>																										
b. "It is difficult to care for people with ID . "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>																										
c. "I need more background information regarding the person with ID than a person without ID. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>																										
d. "I need more training to communicate with people with ID. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>																										
6	A hospital health passport is a document that contains important information regarding the person with ID. Have you encountered a hospital health passport before? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> I don't remember																														
7	Is there a Hospital Information System in your hospital? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> I am not sure																														
8	Would you welcome a situation where the information contained in a hospital health passport is available to you from a secure computer database?																														

“ Each question is optional. Please feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised.”

PART 1

9	Would you be prepared to update such a database if you knew how? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> I am not sure
10	What is your profession? <input type="radio"/> Nurse <input type="radio"/> Doctor
11	What area or ward do you normally work in? _____
12	How long have you worked in the hospital? <input type="radio"/> Less than a year <input type="radio"/> 1-2 years <input type="radio"/> 2-3 years <input type="radio"/> 3-4 years <input type="radio"/> More than 4 years
13	Do you work along with an Advanced Nurse Practitioner? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> I am not sure

“ Each question is optional. Please feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised.”

PART 2

If you are taking care of a person with an intellectual disability who has a hospital health passport, how important are the following information in providing care for the person. Please rate each of the following items on a scale from 1 to 5 by circling the corresponding number.

	Identifying Information	Importance Scale: A numeric scale from 1 to 5. (1) very low importance, (2) low importance, (3) moderate importance, (4) high importance, (5) very high importance				
1	Name	1	2	3	4	5
2	Date of birth	1	2	3	4	5
3	Medical Card Number	1	2	3	4	5
4	Address	1	2	3	4	5
5	Phone number	1	2	3	4	5
6	Type of accommodation or service	1	2	3	4	5
7	Language spoken	1	2	3	4	5
8	Next of kin	1	2	3	4	5
9	Contact details of next of kin	1	2	3	4	5
10	Name of main carer (if different from next of kin)	1	2	3	4	5
11	GP Details	1	2	3	4	5
12	Health Insurance details	1	2	3	4	5
13	Legal representative	1	2	3	4	5

“ Each question is optional. Please feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised.”

PART 2

	Health Information	Importance Scale: A numeric scale from 1 to 5. (1) very low importance, (2) low importance, (3) moderate importance, (4) high importance, (5) very high importance				
14	Current Medication	1	2	3	4	5
15	Allergies	1	2	3	4	5
16	Medical history and treatment plan	1	2	3	4	5
17	Immunisations	1	2	3	4	5
18	Swallowing difficulties	1	2	3	4	5
19	Sensory deficits (e.g. auditory, visual)	1	2	3	4	5
20	How to know if the person is in pain	1	2	3	4	5
21	How the person takes medication	1	2	3	4	5
22	How the person tolerates medical intervention (e.g. injections or examinations)	1	2	3	4	5
23	Family History	1	2	3	4	5
24	Other Services involved in the persons care (Psychiatry, PT, etc.)	1	2	3	4	5
25	Other Medical problems	1	2	3	4	5
26	Advance directives (e.g. DNR) if any	1	2	3	4	5
27	Mens Health (e.g. prostate problems)	1	2	3	4	5
28	Womens Health (e.g. menstrual cycle)	1	2	3	4	5

“ Each question is optional. Please feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised.”

PART 2

	Personal Information	Importance Scale: A numeric scale from 1 to 5. (1) very low importance, (2) low importance, (3) moderate importance, (4) high importance, (5) very high importance				
29	Preferred method of communication (eg. flash cards, picture board)	1	2	3	4	5
30	Signs of anxiety	1	2	3	4	5
31	Support for challenging behaviour	1	2	3	4	5
32	How the person mobilizes (e.g. use of mobility aids)	1	2	3	4	5
33	Level of independence in personal care	1	2	3	4	5
34	Level of independence in using the toilet	1	2	3	4	5
35	Level of independence in feeding	1	2	3	4	5
36	Usual sleep pattern	1	2	3	4	5
37	"Things I like" (person's preference)	1	2	3	4	5
38	"Things I don't like" (person's preference)	1	2	3	4	5
39	Other safety concerns	1	2	3	4	5
40	Person who completed the data set	1	2	3	4	5
41	Level of Intellectual Disability	1	2	3	4	5
42	Ability to give consent	1	2	3	4	5

PART 3

“ Each question is optional. Please feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised.”

Please provide any additional item(s) of information that you feel are essential in assessing people with ID in urgent and emergency care. Please circle the importance of the item in the scale.

	Item	Importance Scale: A numeric scale from 1 to 5. (1) very low importance, (2) low importance, (3) moderate importance, (4) high importance, (5) very high importance				
43		1	2	3	4	5
44		1	2	3	4	5
45		1	2	3	4	5
46		1	2	3	4	5
47		1	2	3	4	5
48		1	2	3	4	5

Any other comments?
