Presenting problems/conditions that result in people with an intellectual disability being admitted to hospitals in the Republic of Ireland

An analysis of NQAIS Clinical data from 2016-2020

September 2021

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In order for acute health services to support people living with intellectual disabilities, there is a need to understand their hospital utilisation and the ‘presenting problems’ in addition to co-existing conditions so as to provide safe and holistic care. This knowledge serves to support the planning of all health services by ensuring that health needs are met at the right time, in the right place to support peoples’ health. International literature acknowledges this knowledge base and this report reflects the first of its kind in the Republic of Ireland. Formal thanks to the Office of the Nursing and Midwifery Service Director and to the Health Service Executive (HSE) in commissioning this report which aids the Irish perspective to be available and, in time no doubt, to be acted upon so as to improve services for this group of people.

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Abbreviations

Abbreviation	*Explanation*
AAIDD	American Association on Intellectual and Developmental Disabilities
ACHI	Australian Classification of Health Intervention
ACS	Australian Coding Standards
ACS*	Ambulatory Care-Sensitive
ANP	Advance Nurse Practitioner
ASD	Autism Spectrum Disorder
CCS	Clinical Classification System
CCU	Coronary Care Unit
CHI	Children’s Health Ireland
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CNS	Clinical Nurse Specialist
COVID-19	Coronavirus Disease 2019
CSO	Central Statistics Office
DoH	Department of Health
DoHC	Department of Health and Children
e.g.	(Latin *exempli gratia*) for example, by way of example, for instance
ED	Emergency Department
EHSREC	Education and Health Science Research Ethics Committee
et al.	(Latin *et alii*) and others
etc.	(Latin *et cetera*) and other things; and so on
GERD	Gastroesophageal Reflux Disease
GIT	Gastrointestinal Tract
GoI	Government of Ireland
HIPE	Hospital In-Patient Enquiry
HPO	Healthcare Pricing Office
HRB	Health Research Board
HSE	Health Service Executive
i.e.	(Latin *id est*) that is (to say)
ICD	International Classification of Disease
ICD-10-AM	International Classification of Disease, 10th Revision Australian Modification

Abbreviation	***Explanation***
ICU	Intensive Care Unit
ID	Intellectual Disability
IDD	Intellectual and Developmental Disability
LENUS	The Irish Health Research Repository
LOS	Length of Stay
NASS	National Ability Supports System
NFVB	National Federation of Voluntary Bodies
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIDD	National Intellectual Disability Database
NPIRS	National Psychiatric In-Patient Reporting System
NPSDD	National Physical and Sensory Disability Database
NQAIS	National Quality Assurance and Improvement System
OpenGrey	System for Information on Grey Literature in Europe
per annum	(Latin) for each year
PET	Patient Experience Times
PFCC	Patient and family-centred care
PP	Presenting Problem(s)
RIAN	Open Access Irish Research Publications
RNID	Registered Nurse Intellectual Disability
RoI	Republic of Ireland
UK	United Kingdom
UNCRPD	United Nations Conventions on the Rights of Persons with Disabilities
USA	United States of America
versus	(Latin) against, as opposed to
WHO	World Health Organization

Executive Summary

The wide range of health conditions and complex needs experienced by people with intellectual disability (ID) means that they are more likely to utilise acute care services in comparison with the general population. ID accounts for 1% to 3% of the world's population and has an onset before the age of 18 years (22 years from an American perspective according to the American Association on Intellectual and Developmental Disabilities (AAIDD) 2021). ID is characterised by lifelong limitations in cognitive and adaptive functioning and experiences of social and environmental restrictions which create barriers to effective participation in daily life. With increased childhood survival rates and improved diagnostic, screening and identification, this percentage has the potential to increase in the coming decades.

There are many clearly identified social and health factors affecting healthcare for people with an ID such as access and utilisation issues, vulnerability to specific health conditions and increasing longevity. These factors suggest that people with an ID are more predisposed to a higher frequency of hospital admissions, longer hospital stays and require additional significant supports. Yet, care provision for people with an ID can at times fall short of acceptable standards, with sub-optimal care reported most often because of a lack of knowledge or skills by healthcare professionals or poor service configuration (Mencap 2012; Mencap 2007).

This report summarises the physical health care needs of people with an ID and highlights the importance of appropriate and timely service delivery planning to meet these unique needs. In addition to communicating difficulties, the experiences of stigma and exclusion among people with an ID requires service providers to consider and accommodate 'reasonable adjustments' to improve health outcomes. Care provision for people with an ID has undergone significant changes in recent decades, with the year 2008 seeing the introduction of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities and to promote respect for their inherent dignity.

Article 25 (Health) of the UNCRPD highlights that people with disabilities have the right to enjoy the highest attainable standard of health and that appropriate measures should be pursued/taken to ensure healthcare services are accessible and available on an equal basis with other members of the general population. The right to healthcare is a central human right and access to relevant healthcare services should be available and accessible as close to the person with a disability's home as possible.

The research project comprises two main elements, namely

1. A literature review
2. Data analysis of hospital admissions 2016–2020

The main findings of the study have identified that

- In the Republic of Ireland (RoI), in the five year period between January 2016 and December 2020 there were 16998 admissions by persons with an identified intellectual disability to acute hospital services;
- People with the following syndromes presented most frequently-Down Syndrome (50%), Chromosomal abnormalities (15%), Microcephaly (7.2%), Di George Syndrome (3.2%) and Tuberous Sclerosis (2.6%); and
- From a physical health perspective, the Top Five 'presenting problems' (PPs) were aligned to the following systems
    1. Respiratory
    2. Gastrointestinal (including teeth)
    3. Neurological
    4. 'Ear Nose Throat and Eyes' and
    5. Cardiac

Integrating the findings of the narrative review and the research the following key recommendations are proffered;

Healthcare Provision Recommendations

1. Given the extensive health needs, communication difficulties, length of hospital stay and use of 'centres of excellence', the necessity to explore and implement 'patient and family-centred care' (PFCC) approaches within acute services is warranted in order for individuals with intellectual disabilities to achieve best health outcomes.
2. The contribution of Family Carers when accessing and engaging with acute health services requires recognition of their role as supporters, communicators and health facilitators.
3. Appropriate healthcare requires inclusive approaches for communication to be timely, accessible and respectful. Technology such as telehealth and video consultations are recommended, in lieu of face to face consultations for people living long distances from centres of excellences or for those with transport difficulties and other responsibilities.
4. The promotion of 'Health Passports' is recommended to support healthcare staff to understand the 'complexity of need' and the 'intersection of support' required by people with intellectual disabilities in order to achieve improved health outcomes. The referral of people with ID, but without a health passport, to a community or liaison Registered Nurse in Intellectual Disability (RNID) to establish a health passport is recommended.
5. This study recommends advancing the community- and liaison-practice role of the RNID to support the health needs of people with an ID and, in particular, 'health promotion, health prevention and health education' interventions through a PFCC model.
6. The study identifies the need and priority areas for the development of advanced and specialist RNID posts to support people with the Top Five presenting problems of respiratory, gastrointestinal, neurological, cardiac and 'ear nose throat and eyes' symptoms/illness.
7. In line with Ireland's national policy, the integration of RNIDs within community, liaison, advanced practice and consultancy roles should occur to support the multidimensional and multidisciplinary service approach required for people with an ID and their families.

Practice Recommendations

1. To aid comparison, decision-making and service planning, an annual review of the profile of admissions of people with an ID to hospital within the NQAIS dataset is required.
2. Clear guidance and agreement for inputting data is required regarding intellectual disability codes. ID codes should not be inputted as the 'presentation problem' or 'cause of death'.
3. The feasibility of recording the 'level of disability' needs to be considered as it should be incorporated into data collection and data coding to assist identification of needs based on complexity.

Policy Recommendations

1. A standardised national approach should be agreed for data categorisation, noting discrepancies between National Ability Support System (NASS) and other Government of Ireland (GoI) agencies *e.g.*, age groupings, definition of ID.
2. Data collection should capture the full presentation and profile of people with intellectual disabilities thus integrating Emergency Department (ED) and mental health admissions information.
3. An annual or biannual report addressing the full profile of presentation, health issues and causes of death in people with intellectual disabilities is recommended to allow for robust monitoring, tracking and evaluation of health(care) information and outcomes.

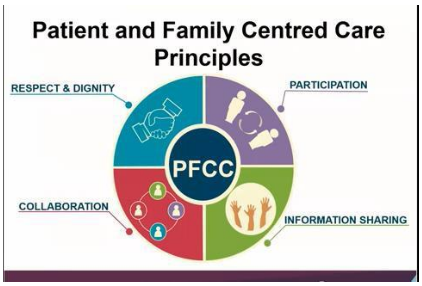
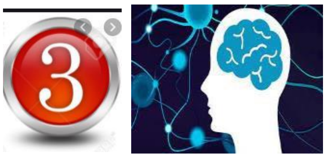
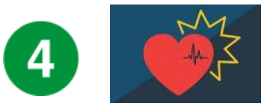
Education Recommendations

1. Education programmes for healthcare professionals addressing communication, assessment, health profile, clinical and behavioural phenotypes for people with an ID should be implemented.
2. Health promotion programmes specific to people with an ID should be developed prioritising the health profiles evident within this report.
3. Familiarisation of the NQAIS clinical dataset is recommended for health and social care practitioners and educationalists, with particular regard to reporting sections within the NQAIS clinical dataset and ICD codes to enhance understanding, recording, analysis and reporting of clinical data.

Future Research Recommendations

1. Future research should be conducted to identify specific issues pertaining to specific conditions, age groups, level of disability and length of stay.
2. A comparison of the health profile of people with an ID as compared with the general population should be conducted.
3. Further analysis on 2020/2021 Coronavirus-19 (COVID-19) data and outcomes needs to be conducted.
4. This research needs to be reinforced by capturing clients/service users and families' perspectives on health, healthcare access, healthcare utilisation and experiences within acute care.
5. Additional research is required to examine over time the cost benefit analyse of any intervention or strategies implemented to support the healthcare needs of people with ID.

Accessible Summary

People with disabilities use hospitals like all other citizens.	
Children and **adults** with intellectual disability may need family support when in hospital. See 'Patient and Family-Centred Care' [*PFCC*] Wright (2018) to explain more, a long video…….but interesting.	https://youtu.be/gvGJs6liD5I 
Sometimes people *have a plan or an appointment* to go to hospital.	
Sometimes there *is no plan or appointment* and you have to rush to get there.	
This research found ***the main*** reasons why people with intellectual disabilities use hospitals in the RoI during 2016–2020. They use them to help with 1. ***Breathing*** problems 2. ***Stomach*** and ***bowel*** troubles 3. Seizures or ***brain*** problems	
	
	
4. ***Heart*** problems (physical-not *love related*!)	

5. 6. Problems with ***ears, nose throat and eyes.***		
Hospitals can be scary for people, and because you are sick, you may not be yourself. Having a ‘health passport’ helps the staff to know you better.		
Have a look at this video ***Explaining*** the benefits of having a health passport.	https://youtu.be/1erY9tb9C7o  Health Passport - Mission Possible	
The HSE is committed to making your experience comfortable and safe. Importantly the HSE is committed to improving your health and well-being and you can have your say.		Your Service Your Say
The research team enjoyed conducting this research – if you want to talk to us contact us directly at.	***Owen at*** ☎ 061-213367 ✉ owen.doody@ul.ie @doody_owen	***Judy at*** 056-7785620 judy.ryan@hse.ie @JudyRyan22

1. Chapter One: Introduction

1.0 Intellectual Disability Context

The recognition of intellectual disability (ID) can be traced back to the Egyptian Papyrus of Thebes of 1552 BC (Doody 2013; Harris 2006). Causes can be unknown, multi-factorial or specific having have sociological, biological and even psychological origins. The range of conditions associated with other developmental limitations have resulted in the broader term ‘Intellectual and Developmental Disability’ (IDD). People with ID/IDD do not constitute a homogeneous group, however, in terms of diagnosis and classification, there are several features accepted across international professional boundaries. The term ID/IDD is internationally accepted to describe significant limitations in both intellectual functioning and in adaptive behaviour which originates before the age of 22 and includes many everyday social and practical skills (Schalock *et al.* 2021).

Intellectual functioning refers to both cognitive functioning and adaptive behaviour. Cognitive functioning relates to learning, reasoning, understanding, and problem solving. Adaptive behaviour refers to conceptual, social and practical skills learned and performed by people in their everyday lives. For the purpose of this report, the term ID is used, with information and literature pertaining to the broader term IDD incorporated.

1.1 Research ‘Terms of Reference’

In December 2020, the HSE invited expressions of interest for the provision of a report based on findings within research, grey literature and the NQAIS clinical dataset. In response, the project team submitted its study proposal and was successfully commissioned to conduct the project over a twelve-week period. The agreed parameters of the project were:

- To use available NQAIS clinical data in order to identify the profile of admissions to acute hospitals across Ireland for people with an ID (age, gender, type of residence);
- To use available NQAIS clinical data to identify the health characteristics of people with an ID admitted to acute hospitals (reason for admission, diagnosis, comorbidity);
- To use available NQAIS clinical data to identify the service characteristics of people with an ID admitted to acute hospitals (length of stay, return admission within 30 days);
- To collate and analyse research and grey literature, and
- To prepare and submit a final project report to the HSE.

1.2 Context of ID in Ireland

There were 28 388 people registered on the National Intellectual Disability Database (NIDD) in December 2017, which represents a prevalence rate of 5.96 per 1000 population (Hourigan *et al.* 2018). This figure may be inaccurate as there is under reporting of diagnoses in people with a mild ID and in children not diagnosed under five years of age. The NASS was established in 2019 and merged both the NIDD and the National and Physical Disability Database (NPSDD). These two Health Research Board (HRB) managed database capture information on disability services used in the RoI and consequently aided the planning, development and organisation of disability services required by people with a disability in their everyday lives.

The establishment of the NASS aimed at supporting a more holistic view of the services which people use and require in their everyday lives and provided information on the population of people who receive or require funded disability services. There are 18 052 people with an ID registered on NASS, of which 9826 (56.2%) are male and 7655 (43.8%) are female.

Ireland's legislative changes since the 1980s have compelled disability policy and strategy to support people with disabilities to live better, healthier and more inclusive lives. Legislation and policies, listed in Table 1.1, show a clear trajectory in the development of individualised and person-centred community-based services.

Table 1.1 Legislation and Strategies

Pertinent Legislation and Strategies in the RoI supporting Disabled People
Needs and Abilities (Department of Health – DoH 1990)
Towards an Independent Future (DoH 1996)
A Strategy for Equality (National Federation of Voluntary Bodies –NFVB 1996)
Disability Strategy (GoI 2004/2017a)
Disability Act 2005 (GoI 2005)
Vision for Change (Department of Health and Children – DoHC 2006)
Citizens Information Act (GoI 2007)
Report of Disability Policy Review (DoHC 2011)
Time to Move on from Congregated Settings (HSE 2011)
Value for Money (DoH 2012)
Progressing Disability Services for Children and Young People (HSE 2012a)
New Directions' (HSE 2012b)
Irish Human Rights and Equality Act (GoI 2014)
Assisted Decision-Making (Capacity) Act (GoI 2015)
A National Framework for Person-Centred Planning in Services for Persons with a Disability (HSE 2018)

Irish legislation and policy have moved towards person-centred care and individualised supports which are recognised to meet the needs of people with a disability and their families. This evolving landscape of service provision which has focuses on health promotion, education and personalisation comprises supported living, independent living, in-home support, community-based support, primary care, and specialist supports (HSE 2011).

An evolving health service model and the personalisation agenda offers the potential for innovative RNID roles to support people with an ID within all areas of healthcare delivery. New roles could include the RNID supporting healthcare in acute hospitals, mental health care services and primary care services in order to support people with an ID in all areas of healthcare delivery (Doody *et al.* 2012). Development of these posts will require a range of agencies working collaboratively to support people with an ID including family members, networks of support offered by friends and social and health care workers across a range of professional disciplines.

Three documents support the development of the RNID roles. First, *Shaping the Future of Intellectual Disability Nursing* in Ireland (McCarron *et al.* 2018) provides the blueprint to improve the health, well-being and social care of people with an ID through expansion of the capacity, capability and leadership of the RNID. Secondly, the *Policy on the Development of Graduate to Advanced Nursing and Midwifery Practice* (DoH 2019a) supports the effective and reimagined use of RNID resources which are needed to fulfil the *Shaping the Future of Intellectual Disability Nursing* (McCarron *et al.* 2018). Thirdly the Sláintecare *Citizen Care Masterplan* (DoH 2019b) focuses on service redesign based on population health planning, current levels of service delivery and collaboration in the development of accessible healthcare services for people with ID. Service redesign must include the evolving role of the RNID to support people with an ID to live ordinary lives in ordinary places.

1.3 Health and Healthcare for People With ID

The lack of reliable information on health conditions experience by people with an ID has been identified as a crucial barrier to the development of successful healthcare strategies for people with an ID (Heslop and Glover 2015). The collection and analysis of good quality data on health conditions experience by people with an ID is essential to influence, shape and resource future planning, policies, services and supports to meet the health needs of people with an ID (McCarron *et al.* 2017).

Currently, there is limited information on the healthcare needs, healthcare utilisation and access to healthcare among people with an ID (Brameld *et al.* 2018). Hence, it is impossible to report on the health status of individuals with ID on a truly representational basis. This is important, as people with an ID are one of our most vulnerable population groups and an understanding of health patterns in the general population has always been a driver in developing priorities for healthcare interventions and monitoring the effectiveness of health services (Hosking *et al.* 2016).

What is widely reported within the literature is that people with an ID experience significantly poorer health than their non-disabled peers on most indicators including self-rated health (Emerson *et al.* 2016; Heslop and Glover 2015). This inequity in health status of people with an ID remains despite the long-acknowledged poorer quality of healthcare delivery to people with an ID (Michael 2008) and the health disparities they experience (Emerson and Baines 2010; O'Hara *et al.* 2010).

What is also known is that people with an ID are more likely to be exposed to well-established social determinants of poor health such as low income, low socio-economic position, poor housing conditions, unemployment, social exclusion, and discrimination (Emerson *et al.* 2016; Taggart and Cousins 2014). Differences in health due social and healthcare inequalities manifest in increased morbidity and multiple morbidity rates (Sandberg *et al.* 2017) which leads to shorter life expectancies, premature deaths (Tomlinson *et al.* 2014; Heslop *et al.* 2013) and higher mortality rates among people with an ID when compared with their non-disabled peers (Heslop *et al.* 2014; Krahn and Fox 2014).

Research identifies that people with an ID die on average 20 years earlier than the background population due to social and healthcare inequalities and comorbidities (Learning Disability Mortality Review 2018; O'Leary *et al.* 2018; Glover *et al.* 2017; Troller *et al.* 2017). This knowledge is further compounded by the fact that many of the deaths reported in the *2013 Confidential Inquiry* into premature deaths of people with an ID in the United Kingdom (UK) were deemed preventable (37%, 90 of 244) had appropriate timely healthcare been provided (Heslop *et al.* 2014).

Additional barriers such as communication difficulties between people with an ID and healthcare personnel creates complexities in access to healthcare and to robust consultations when they do occur (Ward *et al.* 2010). Thereby, people with an ID are more likely to experience inequalities in accessing health care and to die from preventable causes, possibly because of institutional discrimination (Mencap 2012; Michael 2008; Mencap 2007; Disability Rights Commission, 2006). The underlying causes of these barriers and disadvantage in healthcare for people with an ID are multiple, complex and interrelated (Katterl and Bywood 2011; World Health Organisation – WHO 2011). These include biological, physiological, sociological, psychological, educational, economic, communication, physical, and mental health vulnerabilities for people with ID, and attitudes, knowledge and skills of healthcare professionals (WHO 2011; Katterl and Bywood 2011; O'Hara *et al.* 2010).

The lack of reliable information on health conditions and the experience of people with an ID has been identified as a crucial barrier to developing successful healthcare strategies and responses for people with an ID (Heslop and Glover 2015). The provision of good quality information is essential to influence, shape and direct future planning, policies, services, supports and to ensure allocated of effective and sufficient resources to meet the health needs of people with an ID (McCarron *et al.* 2017).

Currently there is limited information on the healthcare needs, healthcare utilisation and access to healthcare among people with an ID (Brameld *et al.* 2018). Thereby generally, it is difficult to report on the health status of individuals with ID on a truly representational basis. This is important, as people with an ID are one of our most vulnerable populations and an understanding of health patterns have been a driver in developing priorities for healthcare interventions and monitoring the effectiveness of health services (Hosking *et al.* 2016).

1.4 Structure of Report

This report, presented over six chapters addresses the background, literature, design, results, discussion, and recommendations as follows:

- Chapter One presents an overview of the topic and project;
- Chapter Two reviews the literature on hospital admissions for people with ID;
- Chapter Three outlines the methodological approach and design of the project and the NQAIS clinical system;
- Chapter Four provides the findings of the profile of the admissions of people with an ID plus health and service characteristics;
- Chapter Five discusses the findings and contextualises these within the wider literature; and
- Chapter Six concludes the report, offering recommendations for healthcare provision, data collection, data management, future analysis, and reporting.

1.5 Chapter Summary

Chapter One presents an overview of the agreed terms of reference for undertaking this research. An introduction to ID highlights the uniqueness and diversity of this group of people, noting the challenges necessity of comprehensive and additional healthcare needs to live ordinary and inclusive lives. The chapter outlines the background of legislation and Governmental strategies and contextualises the provision of support for people with an ID noting that this is a period of ongoing transition within a changing landscape of service provision.

Considerable evidence clearly identifies a disparity between the health status and healthcare of people with an ID to that of the general population. The delivery of safe, person-centred and compassionate care is the responsibility of all health care professionals in primary, secondary and tertiary health care settings. However, it is evident that there is limited information available to report on the health status of individuals with ID on a truly representational basis.

2 Chapter Two: Narrative Literature Review

2.0 Introduction

People who live with an intellectual disability have complex health needs and account for higher proportions of hospital episodes than the general population (Robertson *et al.* 2015; Glover *et al.* 2019). The pattern and type of health needs of people with an ID differs from the general population (Cooper *et al.* 2015). The over-representation of people with an ID in hospitals has been partly attributed to primary care failings to adequately manage their health conditions (Emerson *et al.* 2011). Such conditions include gastrointestinal problems, epilepsy, diabetes, cardiovascular disease, and respiratory problems (Emerson *et al.* 2011). In addition, a readmission within 30 days is an acknowledged indicator of preventable hospital presentations (Kelly *et al.* 2015). Readmission rates are also recognised as an indicator of ineffective discharge planning and transitions of care during hospital stays (Wadhera *et al.* 2019).

Two types of admission rates exist, first, emergency admissions whereby admission is unpredictable and at short notice due to an urgent clinical need and secondly, elective admissions which are planned admissions and where the decision to admit and the actual admission could occur at separate times. Following admission to the acute hospital, a new diagnosis can be made. This is identified as a comorbidity *i.e.,* the diagnosis given to the patient is in addition to the primary diagnosis responsible for initial hospitalisation.

Data pertaining to admission rates and presenting problems/conditions is key to effective service planning and policy development. Access to specific data such as age, gender, reason for admission, residence type, number of previous admissions, comorbidity, and length of stay is essential to achieve optimal health, well-being, and social care of people with ID, as advocated in the national framework and principles for the design of models of care (DoH 2019b) and Sláintecare (GoI 2017b). Meeting the needs of people with an ID requires a redesign of services based on population health data, current levels of service delivery and usage, development of accessible health services (DoH 2019b) and involves building the capacity, capability and leadership of RNIDs (McCarron *et al.* 2018).

2.1 Aim of the Literature Review

The aim of this review was to synthesis international literature on ‘presenting problems’ or conditions which resulted in people with an ID being admitted to acute hospitals and to summarise this knowledge on presenting problems in a comprehensive format according to the acute care journey.

2.2 Review Methodology

A narrative design method was chosen as it provides for a comprehensive overview and broad perspective of a wide range of published literature on a topic (Ferrari 2015). The narrative design facilitates understanding and critiques of current knowledge and summarises a body of literature on an area, identifying gaps and inconsistencies (Noble and Smith 2018). Although there is a wealth of published literature on admission to hospitals, there is a scarcity of empirical studies specific to intellectual disability. This review followed a four-step framework as its methodological approach as it offered a systematic process which incorporates sequential steps which are clear and easy to follow: (1) selecting a review topic, (2) searching the literature, (3) reading, analysing and synthesising the literature, and (4) writing the review (Cronin *et al.* 2008).

The strength of a narrative review is that it synthesises information into a user-friendly format and presents a broad perspective on a subject, its development and management (Noble and Smith 2018).

2.3 Search Methods

A range of literature searching techniques were used to locate literature and existing evidence on admission to acute hospitals for people with ID. Six database searches were conducted in the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Web of Science, Scopus, MEDLINE and at the Cochrane Library. Using ‘intellectual disability’, ‘learning disability’, ‘developmental disability’, ‘acute’, ‘admission’, ‘hospital’, ‘in-patient’, ‘emergency’, ‘elective’, ‘crisis’, and ‘secondary care’ as the key search terms to obtain the greatest coverage of literature. Keywords were searched in ‘title’, ‘abstract’ and combined using Boolean operators “AND” “OR” to broaden and combine searches. Eligibility criteria (Table 2.1) were identified and applied within the screening process to identify peer-reviewed literature published in English.

In addition, the grey literature was searched from national and international sources and supplemented by hand-searching to ensure a comprehensive search strategy. This search included prominent websites. *e.g.*, Central Statistics Office (CSO), HSE, Inclusion Ireland, National Health Service (NHS), National Institute for Health and Care Excellence (NICE), WHO, along with grey literature databases, *e.g.*, The Irish Health Research Repository (LENUS), OpenGrey, Open Access Irish Research Publications (RIAN). While there was an abundance of grey literature offering guidance and best practice recommendations for the care of people with an ID in acute hospital settings (particularly regarding reasonable adjustments), there was little evidence of the reasons why this population engage with acute services or the associated characteristics of this acute services engagement. Therefore, no grey literature met the inclusion criteria for the review.

Table 0.1 Inclusion and exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
Acute care All ages Emergency and elective admissions Intellectual disability population English language publication Timeline: 01-01-2010 –18-01-2021	Non-acute care Data for people with intellectual disability not separately reported or identifiable Non-English publication Data published prior to 2010

2.4 Screening and Analysis

Following the search of the literature, papers were identified for title and abstract screening. Many papers were excluded at this stage as they did not meet the inclusion criteria. Only papers relevant to admission to acute hospitals went forward to the data extraction. Data were mapped onto the framework utilised for this review as identified by the commissioners in their request to quote document, the project team's quotation response document and the agreed terms of reference of the project.

2.5 Synthesis of Findings

In the review of the literature, a synthesis and summary of the findings are presented under the following headings: demographics profile, reason for admission, rate of admission, length of stay, and repeat admissions.

2.6 Demographics Profile

The demographic profile of people with an ID admitted to acute hospital settings varies within the literature and is generally contextualised to personal factors, health conditions and social circumstances (Hand *et al.* 2019a; Hand *et al.* 2019b). Acute hospital admissions are reported across the age continuum from young infant to older adult (Kessler *et al.* 2020). However, the average age of admission for a person with an ID is lower compared with that of the general population (Glover *et al.* 2020; Durbin *et al.* 2018). Chenbhanich *et al.* (2019) reported the mean age of adults at admission was 48.6 years and similarly Chang *et al.* (2017) reports a mean age of 44.9 years. A slightly higher percentage of males compared with females are hospitalised (Lindgren *et al.* 2021; Iancono *et al.* 2020; Chenbhanich *et al.* 2019; Hand *et al.* 2019b; Chang *et al.* 2017).

Admission rates and social circumstances were also intrinsically linked; lower income level status, rural living or being of a minority ethnicity for people with an ID were all linked to higher acute healthcare utilisation rates (Benevidesa *et al.* 2020; Abdullahi *et al.* 2020; Durbin *et al.* 2018; Brameld *et al.* 2018).

2.7 Reason for Admission

Several international studies identified the most common cause of hospitalisation of people with an ID as disorders of the respiratory, gastrointestinal tract (GIT) and nervous system (Iacono *et al.* 2020; Axmon *et al.* 2019; Hand *et al.* 2019a; Brameld *et al.* 2018; Domínguez-Berjón *et al.* 2018; Hosking *et al.* 2017; Ailey *et al.* 2015; Ailey *et al.* 2014). Respiratory disorders included upper and lower respiratory tract infection. Respiratory system diseases noted in the literature included lung diseases due to external agents, influenza, pneumonia, chronic lower respiratory diseases and other acute lower respiratory infections.

Upper respiratory tract conditions affected 58.5% of children admissions and accounted for 12.1% of all admissions in a study in Australia (Fitzgerald *et al.* 2013). A UK study focussed on the adult population highlighted the most common causes of emergency episodes for Ambulatory Care-Sensitive (ACS*) conditions in people with an ID as influenza pneumonia and aspiration pneumonitis (Glover *et al.*, 2020). A Spanish study found that people with a profound ID were admitted to hospital more frequently for respiratory reasons than people without ID (Amor-Salamanca and Menchon 2018). Two people with profound ID in the Amor-Salamanca and Menchon (2018) study died during hospital admission; one from aspiration pneumonitis following admission with fever and the other from broncho-aspiration and respiratory insufficiency following admission with dyspnoea and cough.

Recent studies in the United States of America (USA) and Sweden identified disorders of the GIT with the most common comorbidity of gastroesophageal reflux disease (GERD) and dysphagia (Axmon *et al.* 2019; Chenbhanich *et al.* 2019; Ailey *et al.* 2015; Ailey *et al.* 2014). The presence of a gastrostomy or jejunostomy tube increased the odds of ED presentation (Vencat *et al.* 2011). Gastrostomy tube feeding, tracheostomy tubes, and subglottic stenosis were significantly associated with readmission to acute hospital services (Chenbhanich *et al.* 2019). Furthermore, fluid and electrolyte disorders in children were reported as a common cause of admission to hospital by Lindgren *et al.*, (2021).

Older people with an ID had increased risk of seeking in-patient and outpatient specialist health care for foreign bodies entering through natural orifices as well as for poisoning by drugs, medicaments and biological substances (Axmon *et al.* 2020). Dementia was also associated with increased risk of acute healthcare utilisation (Axmon *et al.* 2016). People with an ID and dementia were reported to have less planned and more unplanned care than those in the general population sample. Findings from this international study highlights the unmet needs of people with an ID and dementia resulting in higher episodes of unplanned care (Axmon *et al.* 2016).

Nervous system disorders which included epilepsy, convulsions and seizures were commonly identified as reasons for admission to hospitals for both children and adults (Lindgren *et al.* 2021; Ahlström *et al.* 2020; Iacono *et al.* 2020; Kessler *et al.* 2020). Common presenting issues to ED for adolescence were convulsions and epilepsy, psychological concerns with depression, emotional disturbance, and psychological or physical distress (Hand *et al.* 2019b). A study conducted in Canada by Durbin *et al.* (2018) found that the most common presenting issues for adults included injuries, poisoning, diseases of the respiratory system, mental, and behavioural disorders.

These findings concur with Blaskowitz *et al.* (2019) in the United States (US) who highlighted that 15% and 3% of the study’s sample were admitted to the hospital for medical and behavioural/psychiatric issues, respectively. Other US studies by Benevides *et al.* (2020) and McDermott *et al.* (2018a) presented similar findings. Benevides *et al.* (2020) reported that 18–28% of ED visits were as a result of injury and 18–25% of ED visits were associated with a psychiatric diagnosis. McDermott *et al.* (2018a) found that at least one comorbid condition was present in 38.0% of those with an ID and ranged from 32.3% for those with mild ID to 47.4% for those with an unspecified ID.

The most common comorbidity indicated for those with a mild and unspecified ID was a mental health condition. A study carried out in Sweden by Ahlström *et al.* (2020) identified that most planned visits (29.4%, n=618) were to an ophthalmology clinic, and most unplanned visits to an internal medicine clinic (36.6%, n=621). The most common cause for planned visits was cataract, found at least once for 32.8% in this cohort, followed by arthrosis (8.9%), epilepsy (8.9%) and dementia (6.6%). Pneumonia, pain, fractures, and epilepsy each accounted for at least one unplanned visit for approximately one-quarter of this population (27.1, 26.9, 26.3 and 19.7% respectively). Urinary tract infections (Hosking *et al.* 2017; Hand *et al.* 2019a; Hand *et al.* 2019b), cardiovascular conditions (Brameld *et al.* 2018) and disorders of the musculoskeletal system (Chenbhanich *et al.* 2019) were also reported.

Reasons for hospital readmissions for older people with an ID who may have higher multi-morbidity compared with the general population included diseases of the nervous system, respiratory, musculoskeletal and connective tissue systems (Axmon *et al.* 2019). Surgical procedures were noted as reasons for admissions for 19 of 70 patients in a US study by Ailey *et al.* (2015). In this study of the 70 patients whose charts were reviewed, complications were noted for 16 (22.9%) following in-patient major surgery and included healthcare-acquired infection, healthcare-acquired skin breakdown, medication errors/reactions, falls and postoperative complications. Findings suggest that adults with ID were twice as likely to have complications. Their health and well-being were further compromised if they had multiple health conditions (Ailey *et al.,* 2015).

2.8 Rate of Admission

There is consensus that the rate of ED attendance for people with an ID is higher than rates for the general population. Studies which compared attendance rates of people with and without ID all identified an increased ED presence for people with ID. However, the rates varied, due to a wide range of variables such as age, sample size and measures. Durbin *et al.* (2018), found that individuals with ID (34%) were more likely than individuals without ID (20%) to visit the ED. Hosking *et al.* (2017) in the UK identified a 3-fold difference of ED admission for people with an ID compared with those without (182 versus 68 per 1000 per year).

Another UK study by Williamson *et al.* (2012) reported a 4% ED rate for people with ID. Venkat *et al.* (2011) in the US found that adults with ID accounted for 51% of ED presentations, while Hand *et al.* (2019a) identified rates of ED visits as between 25% and 32%, which is significantly higher than the national average of the general population at 22%.

Similar to ED visits, there is a marked increase in the utilisation of in-patient services among children (Amor-Salamanca and Menchon 2018; McDermott *et al.* 2015; Bebbington *et al.* 2013; Fitzgerald *et al.* 2013) and adults (Glover *et al.* 2020; Glover *et al.* 2019) with ID. In-patient rates vary greatly 30.5% (Venkat *et al.* 2011), 39.4%-50.6%, (Hand *et al.* 2019b), 40% (Jensen and Davis 2013), 33% (Chenbhanich *et al.* 2019) and 85.7% (Domínguez –Berjón *et al.* 2018). One Australian study by Fitzgerald *et al.* (2013) found that on average, children had an estimated rate of 757.2 admissions per 1000pyr (per year rate). A US study by Lindgren *et al.* (2021) found that from a sample of 15 417 inpatients admissions of children with an ID, 5.1% had a minimal of one hospital admission.

2.9 Length of Stay

Within the literature, there is ample international evidence identifying a longer length of stay (LOS) for people with an ID in acute care hospital settings, as compared to matched controls within the general population (Glover *et al.* 2020; Chenbhanich *et al.* 2019; Amor-Salamanca and Menchon 2018; Chang *et al.* 2017). The average LOS in an acute hospital setting is a measurable variable often used as an indicator of health system utilisation and efficiency (Baek *et al.* 2018). The average LOS for people with an ID compared with people without ID for similar conditions and procedures is an important comparison which often highlights health disparities. Children and adults with ID once admitted to acute care, generally spend a longer time as an in-patient (Glover *et al.* 2020).

Iancono *et al.* (2020) found that almost half (49%) of those who visited the ED were admitted. Chang *et al.* (2017) reported that the duration of hospitalisation was significantly longer for people with an ID when compared with controls (2.34 days longer). In the USA, Chenbhanich *et al.* (2019) reports the average LOS as 3.9 to 7.7 days for people with Down Syndrome as compared with 4.34 days for the general population. McDermott *et al.* (2018a) reports an average LOS of 4.9 days for ACS* admissions for people with ID.

Similarly, findings in Australia by Fitzgerald *et al.* (2013) reported an average LOS of 3.8 days for children with Down Syndrome, with durations of one day or less recorded in 56.4% of admissions and 95.3% of admissions were of 14 days or less over a seventeen-year time period. Comparable statistics and longer stay durations for people with an ID are reported by Glover *et al.* (2020) in an English based observational cohort study, which identified an average LOS of 3.5 days compared to 3.1 days for people without ID. Furthermore, a Spanish study by Domínguez-Berjón *et al.* (2018) described LOS specific to presenting conditions/problems in people with an ID and reported that for oral/dental care, the median length of stay was 1.0 day, for orthopaedic problems, the median length of stay was 2.5 days and for acute respiratory disorder, the median length of stay was 8.5 days.

2.9 Repeat Presentations/Admissions

Repeat hospital presentations for people with an ID are a concern (Kessler *et al.* 2020; McDermott *et al.* 2018a; Domínguez -Berjón *et al.* 2018; Reppermund *et al.* 2017). Readmissions within 30 days are reported by Iacono *et al.* (2020) and Axmon *et al.* (2019). Lindgren *et al.* (2021) found that 5.1% of children with ID had two repeat admissions and 1.1% had three repeat admissions within a one-year period.

2.10 Chapter Summary

Chapter Two reviewed the literature on hospital admissions for people with ID. People with an ID are admitted to acute hospitals for a wide range of health conditions, the most prevalent problems include disorders of the respiratory, GIT, nervous, and musculoskeletal system. The literature confirms that people with an ID present more frequently to EDs, have higher rates of admission, and often once admitted have longer LOSs in hospital than the general population.

Worryingly, repeat presentation and readmissions after discharge for the same problem are also higher than that of the general population and this signifies a serious concern for the care provided to this vulnerable group. Complications following medical and surgical interventions and avoidable premature death must also be explored and prevented. Within the review, all the acute hospital indicators signal health disparities for people with an ID and a trail of unmet acute healthcare needs. In an Irish context, within the evolving landscape of service provision and the personalisation agenda, it is imperative that the philosophy of equitable care regarding accessing and utilising acute healthcare services be upheld and prioritised for people with ID.

3 Chapter Three: Design and Evaluation Process

3.0 Introduction

The delivery of safe, reliable healthcare depends on access to, and the use of, information which is accurate, valid, reliable, timely, relevant, legible and complete. The NQAIS clinical database is an online interactive application which analyses hospitals' own Hospital In-Patient Enquiry (HIPE) data in order to provide detailed feedback to clinicians, researchers and hospital administrators. This health information plays an important role in healthcare planning and decision-making for health and social care provision, for example, as to where to locate a new service, or whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision. Responsibility for service planning requires the gathering of accurate and reliable information to make informed decisions. This research study provides data to support service planning and decision-making pertaining to intellectual disability support services.

NQAIS clinical data on admissions from 2016–2020 of children and adults with ID to Irish hospitals plus their reason for admission or PP were examined. In addition, data pertaining to admission type, length of stay, secondary diagnosis (up to 30), mortality, discharged to and readmission rates were reviewed, analysed and discussed. Anonymity for patients and healthcare teams is guaranteed as names of patients and clinicians are not stored in the data. Furthermore, the NQAIS clinical website is encrypted and users must gain authorisation and use unique identifiers and passwords to gain access to data.

3.1 Aim of the Project

The overall aim of the research has been to examine the admissions rates and presenting problems of people with an ID to Irish public hospitals during the period 2016–2020 using data recorded in the NQAIS clinical database.

3.2 Objectives

Research objectives are to:

- Profile the admission of people with an ID by age, gender and from where the person has come;
- Identify the route of entry to the hospital *i.e.*, emergency or elective;
- Detail the purpose of the admission, known as the 'presenting problem'; and
- Define characteristics of the hospital stay: length of stay, return admission if within 30 days,
- Present data in a summarised accessible format.

3.3 Methods

The methods undertaken within this project involve extracting and analysing the NQAIS clinical dataset. This involved identifying the database variables, accessing the database, ethical approval, identifying coding classification, NQAIS clinical training, and identifying activities not collected.

3.3.1 Database and Variables

The NQAIS clinical database collects and hosts HIPE data of discharged patients from acute hospitals in Ireland and records all hospital admissions nationally. Data displayed within NQAIS clinical database belong to the hospitals and hospital groups. Robust governance structures are in place for the appropriate use of NQAIS clinical. Access to the data is now detailed.

3.3.2 Accessing NQAIS Database

NQAIS clinical data are available on the Health Atlas Ireland homepage at www.healthstlasireland.ie and are accessible to registered users who have been provided with authorisation. User agreements were provided to Dr Doody, the principal investigator, and to the two team members, Dr Ryan and Dr McMahon by the HSE on 27 January 2021. Access to NQAIS clinical national data was authorised for research purposes. The user agreement detailed data confidentiality and specific system access.

3.3.3. Ethical Considerations and Gatekeeper Supports

Ethical approval was sought from the University of Limerick's Education and Health Science Research Ethics Committee (EHSREC) with approval granted on 4th February 2021 reference number: 2021_02_21_EHS (OA), [Appendix 1]. 'Access Controller' Eilish Croke, Programme Manager NQAIS clinical database, provided authorised users individual identifiers and passwords in addition to training material, online tutorials and follow-up support.

3.3.4 Hospital In-Patient Enquiry

The Hospital In-Patient Enquiry (HIPE) system is the only national source of morbidity statistics available for acute hospital services in Ireland. All acute public hospitals participate in HIPE reporting and over 1.5 million records are created annually (Healthcare Pricing Office – HPO 2021). The main function of the HIPE is to detail the correlation and collection of data on discharges from, and deaths in acute hospitals and input this data onto the national HIPE database.

A HIPE discharge record is created when a patient is discharged from or dies in hospital. This record contains administrative, demographic and clinical information for a discrete episode of care. An episode of care begins at admission to hospital and ends at discharge from or death in that hospital (HPO 2021). HIPE is thus the principal source of national data on discharges from acute hospitals in Ireland.

3.3.5 HIPE Clinical Coding – The Coding Process

The source document for HIPE coding is the patient record or chart. A clinical coder, a trained person translates medical, nursing and allied health care terminology within the patient records into alpha-numeric code. Documentation used for coding a case includes the discharge summary or letter, nursing notes, consultation reports, progress notes, operative reports, pre-and post-operative reports and pathology reports. The clinical coder follows five steps in coding quality (HPO 2021) and uses the entire chart to extract the conditions and procedures in order to draw an accurate picture of the patient and their health care encounter.

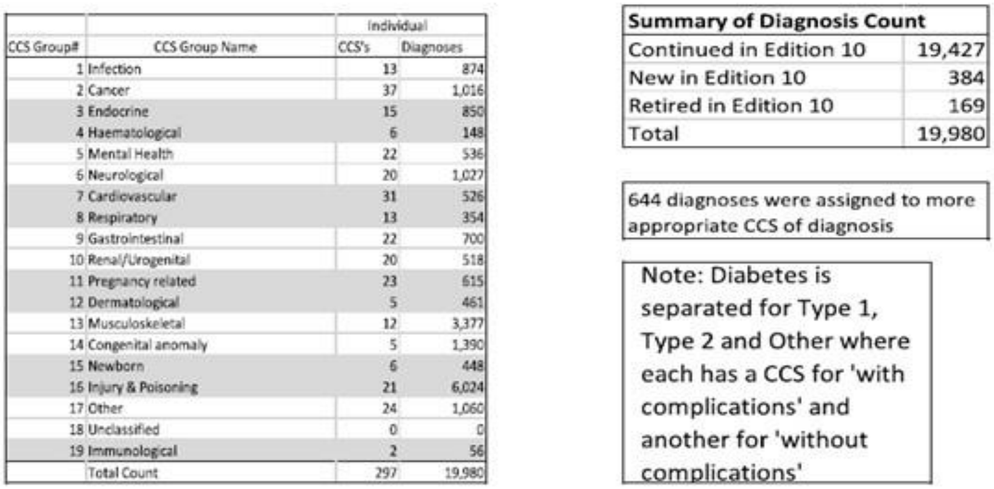
3.3.6 HIPE Data Quality, Audit and Training

A clinical coding support team in the HIPE Unit provides data quality, audit and training to all HIPE coders in Ireland. They also provide education and support to HIPE users on all aspects of the system ensuring the reliability and robustness of the data entry processes.

3.3.7 HIPE Coding Classification used in Ireland (ICD-10-AM / ACHI / ACS)

ICD-10-AM is the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification. The ICD-10-AM disease component is based on the World Health Organisation ICD-10. ICD-10-AM is used in conjunction with the Australian Classification of Health Interventions (ACHI), and the Australian Coding Standards (ACS) to reflect an accurate health episode of care.

- The 4th edition of this classification was introduced for all discharges from 1 January 2005 and was selected as the best integrated coding scheme for diagnoses and procedures available internationally;
- The 6th Edition of ICD10-AM/ACHI/ACS was used to code all discharges from 1 January 2009 to 31 December 2014;
- Ireland updated to the 8th Edition of ICD-10-AM/ACHI/ACS for all discharges from 1 January 2015. Using this classification approach, 19 groups of diagnoses and 297 Clinical Classification System (CCS) of Diagnosis are utilised as per Figure 3.1.



		Individual	
CCS Group#	CCS Group Name	CCS's	Diagnoses
1	Infection	13	874
2	Cancer	37	1,016
3	Endocrine	15	850
4	Haematological	6	148
5	Mental Health	22	536
6	Neurological	20	1,027
7	Cardiovascular	31	526
8	Respiratory	13	354
9	Gastrointestinal	22	700
10	Renal/Urogenital	20	518
11	Pregnancy related	23	615
12	Dermatological	5	461
13	Musculoskeletal	12	3,377
14	Congenital anomaly	5	1,390
15	Newborn	6	448
16	Injury & Poisoning	21	6,024
17	Other	24	1,060
18	Unclassified	0	0
19	Immunological	2	56
	Total Count	297	19,980

Summary of Diagnosis Count	
Continued in Edition 10	19,427
New in Edition 10	384
Retired in Edition 10	169
Total	19,980

644 diagnoses were assigned to more appropriate CCS of diagnosis

Note: Diabetes is separated for Type 1, Type 2 and Other where each has a CCS for 'with complications' and another for 'without complications'

Figure 3-1 Clinical Classification System (CCS) of Diagnosis

3.3.8 Activities Not Currently Collected by HIPE

It is important to note that clinical and therapeutic activities where people with an ID may experience healthcare provision are not recorded within the NQAIS clinical database. The list of healthcare activities where HIPE is not collected include:

- Out-patient activity;
- Clinics;
- Virtual wards (Note, pilot to collect virtual ward activity has ended);
- Accident and Emergency (A&E)/ED activity data on patients on trollies in in-patient wards collected by HIPE. There must also be a corresponding in-patient admission on the PAS;
- Well babies;
- Elective admissions to Acute Medical Assessment Units and/or Elective admissions to Acute Surgical Assessment Units are not valid HIPE activity and are reported as outpatient activity;
- Clinics such as education clinics, pre-assessment clinics, dressings clinics or other such clinics are not valid HIPE activity and are not reported to HIPE regardless of where performed;
- Colposcopies performed as part of the National Cervical Screening Programme are not reported to HIPE; and
- Discharge lounges such as transit wards or transit lounges (Irish Coding Standards 2021).

3.3.9 Inclusion and Exclusion Criteria

All adults and children with intellectual disability (Appendix 2) coded in NQAIS clinical Column K or L admitted to hospital between January 2016–December 2020 were included. Patients who did not have a specific ID were not included.

3.3.10 Data Collection

Data for this study was downloaded from the NQAIS clinical database, reflecting the healthcare classifications within patient's charts or records coded by trained clinical coders in hospitals. NQAIS clinical data from January 2016 to December 2020 were included from all the hospitals identified in Table 3.1.

Table 3.1 List of RoI Hospitals

NQAIS clinical records reviewed from January 2016-December 2020	
Bantry General Hospital	Midland Regional Hospital Mullingar
Beaumont Hospital (incorporating St Joseph's Raheny, St Luke's Radiation Oncology Centre)	Naas General Hospital
Cappagh National Orthopaedic Hospital	Our Lady's Hospital, Navan
Cavan Monaghan Hospital	Nenagh Hospital: University of Limerick (UL) Hospitals
Connolly Hospital Blanchardstown	Portiuncula Hospital, Ballinasloe
Coombe Women's Hospital	Midland Regional Hospital Portlaoise
Cork University Hospital	St Luke's Hospital, Rathgar (Cancer Services)
Cork University Maternity Hospital	Roscommon County Hospital
Our Lady's Children's Hospital Crumlin	Rotunda Hospital
Our Lady of Lourdes Hospital, Drogheda	Royal Victoria Eye and Ear Hospital, Dublin
Ennis Hospital: UL Hospitals	Sligo General Hospital
Galway University Hospitals	South Infirmary-Victoria Hospital, Cork
National Maternity Hospital, Holles Street	St Colmcille's Hospital, Loughlinstown
Kerry General Hospital	St John's Hospital, Limerick
Lourdes Orthopaedic Hospital, Kilcreene	St Luke's General Hospital Carlow / Kilkenny
Letterkenny University Hospital	St Michael's, Dun Laoghaire
University Maternity Hospital: UL Hospitals	St James's Hospital (incorporating St Luke's Radiation Oncology Centre)
University Hospital Limerick	St Vincent's University Hospital, Elm Park
Louth County Hospital, Dundalk	South Tipperary General Hospital
Mallow General Hospital	Tallaght University Hospital (incorporating Children's Health Ireland (CHI) at Tallaght)
Mater Misericordiae University Hospital	Children's University Hospital, Temple Street
Mayo General Hospital	Midland Regional Hospital Tullamore
Mercy University Hospital, Cork	University Hospital Waterford
	Wexford General Hospital

Data downloaded was presented across 20 columns representing the patient within the NQAIS clinical databases. Each Column represents specific criteria as outlined in Table 3.2.

Table 3.2 NQAIS downloaded data format

Column	Identifying
A	Hospital where patient was admitted
B	Place where person came from [home, nursing home or other]
C	Admission stream [emergency or elective]
D	Discharge to [home, nursing home, other hospital or other]
E	Patient’s age
F	Patient’s gender
G	Presenting problem [principal admission diagnosis]
H	Co-morbidities [up to 30 can be recorded and aids determining clinical complexity]
I	Primary procedures and interventions
J	Additional coding procedures and interventions
K	Code for Presenting problem [principal admission diagnosis]
L	Code(s) for co-morbidities [up to 30 can be recorded and aids determining clinical complexity]
M	Primary procedures and interventions code
N	Additional coding procedures and interventions codes
O	Charlson score
P	Palliative care [Yes/No]
Q	Length of Stay
R	Intensive Care Unit (ICU) / Coronary Care Unit (CCU) bed-days
S	Readmission < 30days [Yes/No]
T	Readmission information

3.4 Chapter Summary

To meet the aims of this project, a clear methodological process was used to explore reasons for and characteristics of persons with ID admitted to acute hospitals in Ireland. The chapter outlines the project design, ethics, data collection and data analysis process.

4 Chapter Four: Findings

4.0 Introduction

Findings, from analysis of the dataset extracted from the NQAIS clinical database pertaining to hospital admission in the RoI of people who have an identifiable intellectual disability, are now presented. The data were from the years 2016, 2017, 2018, 2019, and 2020 as extracted from the NQAIS clinical database in March 2021. The 2020 data were not yet fully validated by the HPO when this work was completed.

4.1 Findings

The findings are reported in line with the research objectives which are to:

- Profile the admission of people with an ID by age, gender and from where the person has come;
- Identify the route of entry to the hospital *i.e.*, emergency or elective;
- Detail the purpose of the admission, known as the 'presenting problem';
- Define characteristics of the hospital stay: length of stay, return admission if within 30 days;
- Present data in a summarised accessible format.

4.1.1 Profile of admissions

In the five-year period, male admissions accounted for a slightly higher percentage (n=9007, 53%) than female admissions (n=7991, 47%). Nearly three quarters of the population admitted to hospital were under the age of 18 (n=12654, 74.5%) and the remaining quarter (3624, 25.6%) in the adult age group. The age of the population ranged from 0 up to 90 (n=3) years of age with a total of 33 people over the age of 80 years of age. Table 4.1 details age demographics.

Table 4.1 Age profile of population

Frequencies for Age Group			**Child/Adult**		
Age Group	**Frequency**	**Per cent**			
0-5 years	7695	45.3	**Child**		
6-12 years	3400	20.0	**Age Group**	**Frequency**	**Per cent**
13-18 years	1559	9.2	**0-18**	12654	74.5
19-25 years	608	3.6	**Adult**		

26-40 years	1196	7.0	**Age Group**	**Frequency**	**Per cent**
41-59 years	1919	11.3	**19+**	3624	25.6
60+	621	3.7			
Total	**16998**	**100.00**		**16998**	**100.00**

Within the population admitted to hospital, the Top Five intellectual disability conditions were Down Syndrome, Chromosomal conditions, Microcephaly, DiGeorge Syndrome, and Tuberous Sclerosis. Table 4.2 identifies the intellectual disability conditions of the admitted cohort between the years 2016 and 2020.

Table 4.2 Intellectual disability Profile

Condition	**Number**	**Condition**	**Number**
Down Syndrome	8494 (50%)	Rubenstein-Taybi	90 (0.5%)
Chromosomal	2542 (15%)	Fragile X Syndrome	74 (0.4%)
Microcephaly	1228 (7.2%)	Toxoplasmosis	62 (0.4%)
DiGeorge syndrome	544 (3.2%)	Patau's Syndrome	50 (0.3%)
Tuberous Sclerosis	436 (2.6%)	Cornelia de Lange Syndrome	48 (0.3%)
Niemann-Pick Disease	398 (2.3%)	Karyotype	47 (0.3%)
Hurler Syndrome	389 (2.3%)	Sotos Syndrome	41 (0.2%)
Prader-Willi Syndrome	299 (1.7%)	Lawrence-Moon-Biedl syndrome	33 (0.2%)
Rett Syndrome	287 (1.6%)	Edwards Syndrome	27 (0.2%)
Turner Syndrome	246 (1.4%)	Lesch-Nyhan Syndrome	24 (0.1%)
Canavan	243 (1.4%)	Smith-Lemli-Opitz	21 (0.1%)
Lissencephaly	188 (1.1%)	Triple X Syndrome	18 (0.1%)
Angelman Syndrome	172 (1.0%)	Tay-Sachs Syndrome	16 (0.1%)
Apert Syndrome	159 (0.9%)	Batten Disease	15 (0.1%)
Klinefelter Syndrome	121 (0.7%)	Anencephaly	< 5 (0.0%)
Williams Syndrome	120 (0.7%)	Rubella	< 5 (0.0%)
Hunter Syndrome	102 (0.6%)	West Syndrome	< 5 (0.0%)
Wolf-Hirschhorn Syndrome	94 (0.5%)	Cockayne Syndrome	< 5 (0.0%)
Cri du chat Syndrome	92 (0.5%)	**Total**	**16998**

Within the unspecified intellectual disability conditions *e.g.*, chromosomal conditions, it was possible to identify associated developmental disability conditions, the Top Four of which were neurofibromatosis, failure to thrive, cerebral palsy and autism spectrum disorder (Table 4.3).

Table 4.3 Associated developmental disability conditions

Condition	Number	Condition	Number
Neurofibromatosis	486	Neurodevelopmental*	12
Failure to thrive	466	Homocystinuria	< 5
Cerebral Palsy	448	Spina bifida	< 5
Autism Spectrum Disorder (ASD)	355	Foetal Alcohol Syndrome	< 5
Hypothyroidism	18	Galactosaemia	< 5
Sandhoff	16	Phenylketonuria	< 5

In line with the juvenile age profile of those admitted to acute hospitals, the Top Five admitting hospitals consisted of the three children's hospitals Crumlin (1), Temple St (2) and Tallaght (5) with University Hospitals Cork (3) and Galway (4) making up the other two hospitals. These five hospitals accounted for 58.1% (n=9872) of all admissions. Table 4.4 identifies the admissions of people with an ID to all hospitals in Ireland from January 2016 to December 2020.

Table 4.4 Admitting hospital

Hospital	Frequency	Per cent	Hospital	Frequency	Per cent
CHI at Crumlin	4583	27.0	St Luke's Kilkenny	161	0.9
CHI at Temple St	2047	12.0	Wexford	153	0.9
Cork UH	1488	8.8	Rotunda	142	0.8
Galway UH	1086	6.4	NMH Holles St	109	0.6
CHI Tallaght	668	3.9	St Vincent's UH	103	0.6
UH Limerick	623	3.7	Mallow	94	0.6
Mayo UH	484	2.8	Coombe UH	90	0.5
Mercy UH	460	2.7	South Tipperary	85	0.5
Portiuncula UH	383	2.3	Navan	56	0.3
Sligo UH	363	2.1	Limerick UMH	53	0.3
UH Waterford	358	2.1	Tullamore	48	0.3
Tallaght – Adults	352	2.1	St John's	42	0.2
Letterkenny UH	330	1.9	Bantry	27	0.2
OLOL Drogheda	325	1.9	Roscommon	25	0.1
Beaumont	320	1.9	Nenagh	23	0.1
Portlaoise	288	1.7	St Colmcille's	20	0.1
Mater UH	243	1.4	Ennis	15	0.1
Cavan	226	1.3	St Michael's	< 5	0.0
UH Kerry	202	1.2	Cappagh	< 5	0.0
Connolly	188	1.1	Croom	< 5	0.0
South Infirmary VUH	184	11	Louth	< 5	0.0
Mullingar	182	1.1	St Joseph's Raheny	< 5	0.0

Hospital	**Frequency**	**Per cent**	**Hospital**	**Frequency**	**Per cent**
Royal Vic EandE	174	1.0	SLRON Rathgar	< 5	0.0
St James's	174	1.0	**Total**	**16998**	**100.0**

4.1.2 Type of admission

Of the admissions, 87.7% (14914) were admitted from home with the remaining admissions recorded as a transfer from another hospital such as maternity, psychiatric, hospice, and other acute/non-acute hospitals. Within the remaining admissions grouping, 3.3% (n=545) were from nursing/convalescent/other long stay accommodation, temporary place of residence or identified as other. Table 4.5 identifies the 'admission from' data.

Table 4.5 'Admitted from'

Admitted from	**Frequency**	**Per cent**	**Admitted from**	**Frequency**	**Per cent**
Home	14914	87.7	Transfer from Non-Acute Hospital not in HIPE hospital listing	36	0.2
Transfer from Acute Hospital	931	5.5	Temporary place of residence	12	0.1
New-born	563	3.3	Transfer from psychiatric hospital/unit	6	0
Transfer from nursing 1/convalescent 1 or other long stay accommodation	469	2.8	Transfer from hospice not in HIPE hospital listing	< 5	0
Other	64	0.4	**Total**	**16998**	**100.0**

The highest percentage of admissions were elective admissions (n=9358, 49.2%) and when elective readmissions are included, this accounts for over half of the admissions (n=8953, 52.7%). Emergency admission/readmissions accounted for 7090 (41.7%) with the remaining 955 (5.6%) new-born or maternity admissions (Table 4.6).

Table 4.6 Admission type

Type of Admission	**Frequency**	**Per Cent**	**Type of Admission**	**Frequency**	**Per Cent**
Elective	8358	49.2	Elective Readmission	595	3.5
Emergency	6948	40.9	Emergency Readmission	142	0.8
New-born	918	5.4	Maternity	37	0.2
			Total	**16998**	**100.0**

The majority 89.6% (n=15223) of people with an intellectual disability were discharged to their home. Full discharge data are outlined in Table 4.7.

Table 4.7 Discharge profile

Discharged to	**Frequency**	**Per cent**	**Discharged to**	**Frequency**	**Per cent**
Home	15223	89.6	Transfer to Non-Acute Hospital not in HIPE	29	0.2
Nursing home, convalescent home or long stay accommodation	619	3.6	Hospice (not in HIPE Hospital Listing)	22	0.1
Transfer to Hospital – Non-Emergency	456	2.7	Temporary place of residence (*e.g.*, hotel)	9	0.1
Transfer to Hospital – Emergency	301	1.8	Transfer to external rehabilitation facility (not in HIPE Hospital Listing)	7	0
Died no post-mortem	234	1.4	Transfer to psychiatric hospital/unit	6	0
Died with post-mortem	55	0.3	Other (*e.g.*, foster care)	< 5	0
Self-discharge	33	0.2	**Total**	**16998**	**100.0**

4.1.3 Presenting problems

The ‘Presenting Problems’ detailed in the NQAIS clinical dataset Column K (Dx 1 ICD code) are now presented. In all, 16 categories aligned to the NQAIS clinical dataset and ICD codes were utilised to represent the data. Figure 4.1 presents the main findings of the ‘presenting problems’ which people with an ID were admitted to hospitals with in the RoI during 2016–2020.

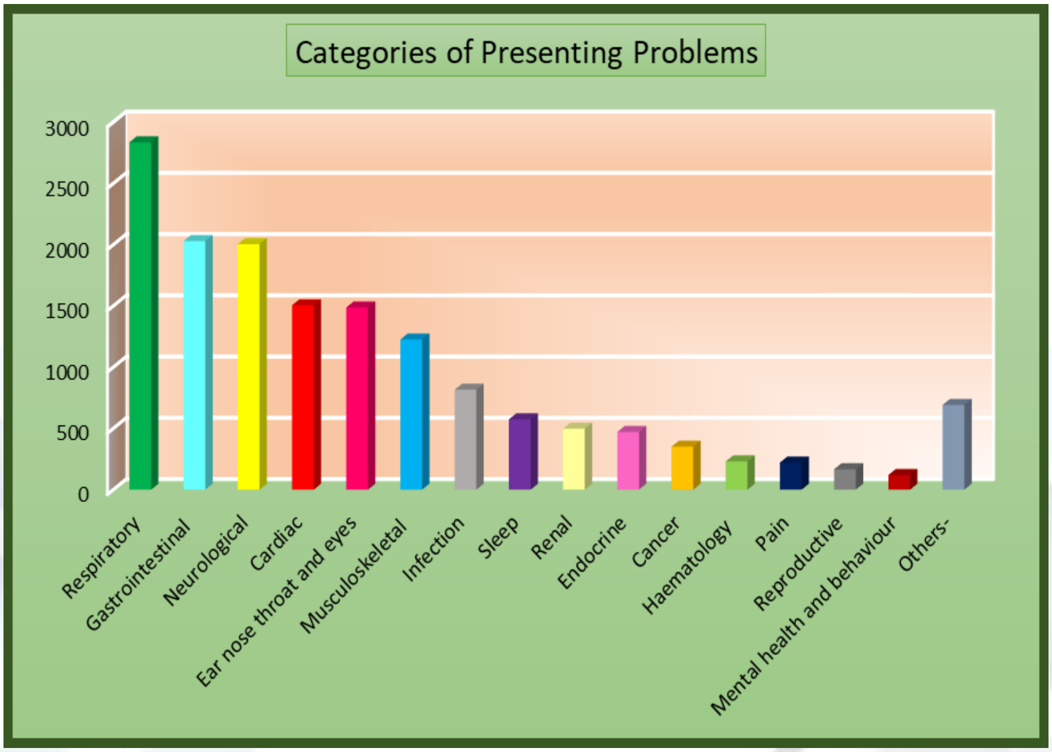


Figure 4-1 Categories of Presenting Problems

Sample characteristics for the Dx 1 ICD coded data presented in the dataset are presented in Table 4.8.

Table 4.8 Presenting Problem – Column K (Dx 1 ICD code)

Category	***Number of people admitted with Presenting Problems***	***Number of Conditions code-related to presenting problems***
Respiratory	2835	118
Gastrointestinal	2029	194
Neurological	2004	143
Cardiac	1505	155
Ear nose throat and eyes	1487	191
Musculoskeletal	1226	350
Infection	816	166
Sleep	574	11
Renal	498	41
Endocrine	471	53
Cancer	351	79
Haematology	231	54
Pain	221	22
Reproductive	167	167
Mental health and behaviour	119	33
Others-	692	65
Intellectual Disability inputted as opposed to PP [*e.g.* Q909, other trisomies: F842 and Others]	1772	
Total	**16998**	**1842**

Analysis within each NQAIS category of admission identified top-rated conditions. The respiratory category (n=2835) comprised of 118 codes, of which the Top Seven presenting problems were respiratory infections, pneumonia and breathing abnormalities. These are detailed in Figure 4.2.

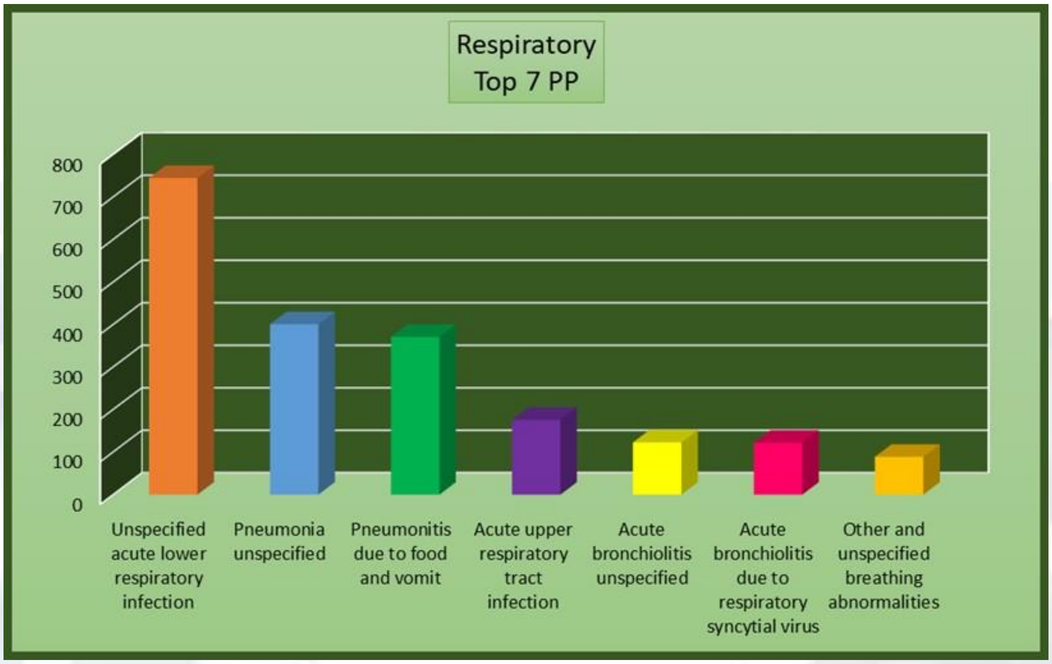


Figure 4-2 Respiratory Top Seven Presenting Problems

The second category, Gastrointestinal (n=2029), comprises of 194 gastro-and intestinal-related codes. The Top Seven codes are nausea, vomiting, gastroenteritis, dental caries, constipation, and feeding difficulties. These are detailed in the Figure 4.3.

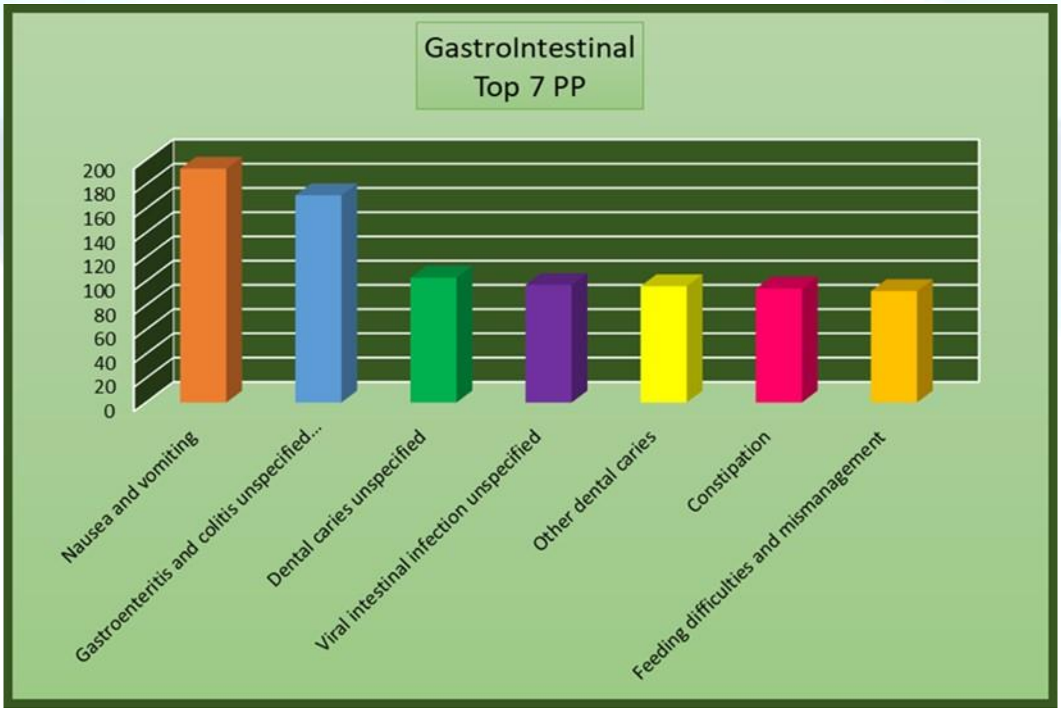


Figure 4-3 Gastrointestinal Top Seven Presenting Problems

The third category, Neurological (n=2004) comprises 143 neurological-related codes. The Top Seven presenting problems are detailed in the Figure 4.4.

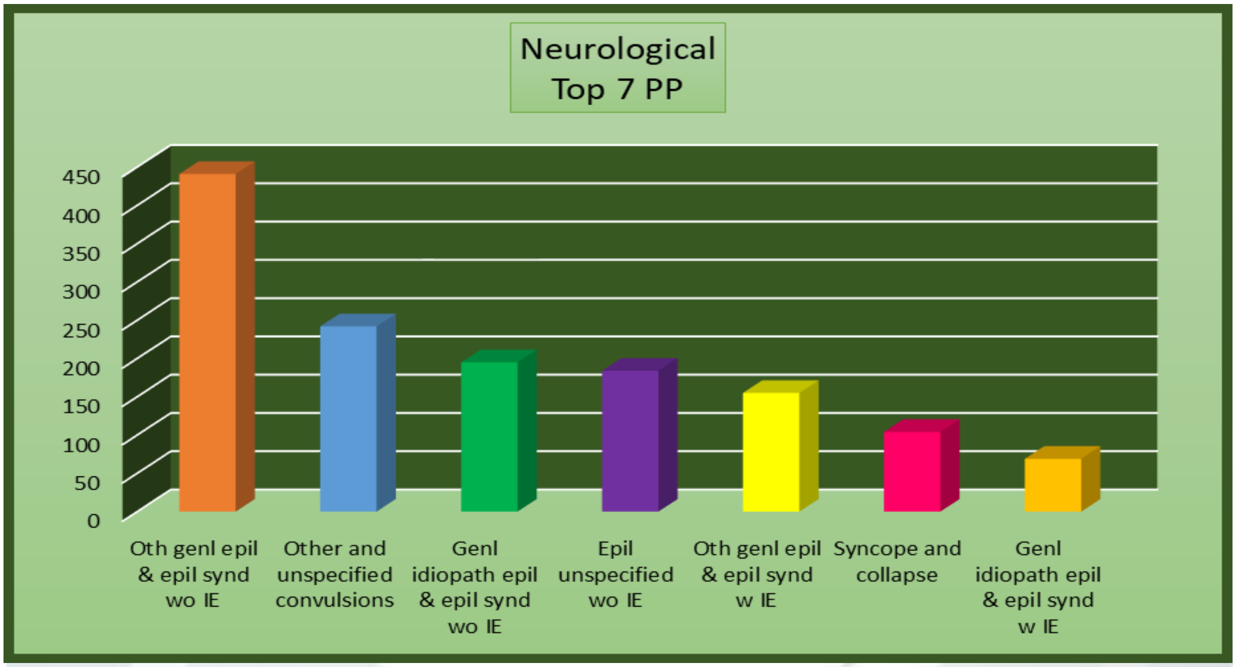


Figure 4-4 Neurological Top Seven Presenting Problems

The fourth category, Cardiac (n=1505) comprises of 155 cardiac-related codes. The Top Seven presenting problems are detailed in Figure 4.5.

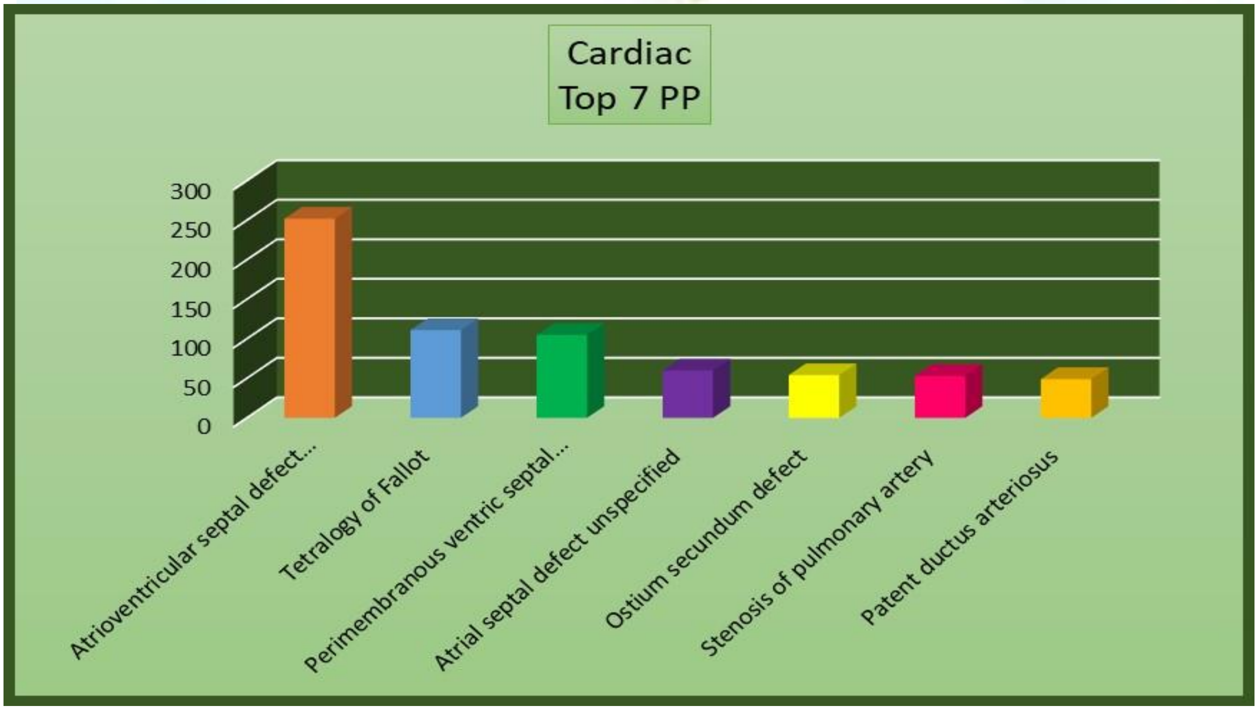


Figure 4-5 Cardiac Top Seven Presenting Problems

The fifth category, Ear Nose Throat and Eyes (n=1487) comprises of 191 ‘ENT and Eyes’-related codes with the Top Seven presenting problems detailed in the Figure 4.6.

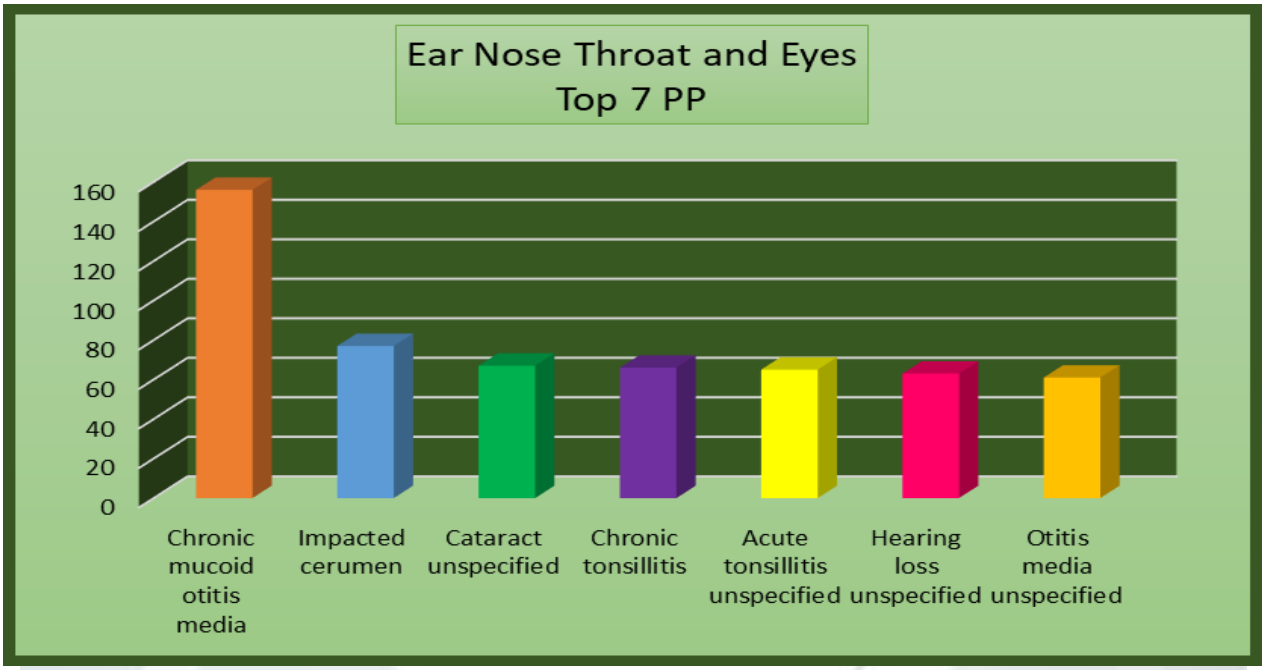


Figure 4-6 Ear Nose Throat and Eyes Top Seven Presenting Problems

The sixth category, Musculoskeletal (n=1226) comprises of 350 musculoskeletal-related codes with the Top Seven presenting problems detailed in the Figure 4.7.

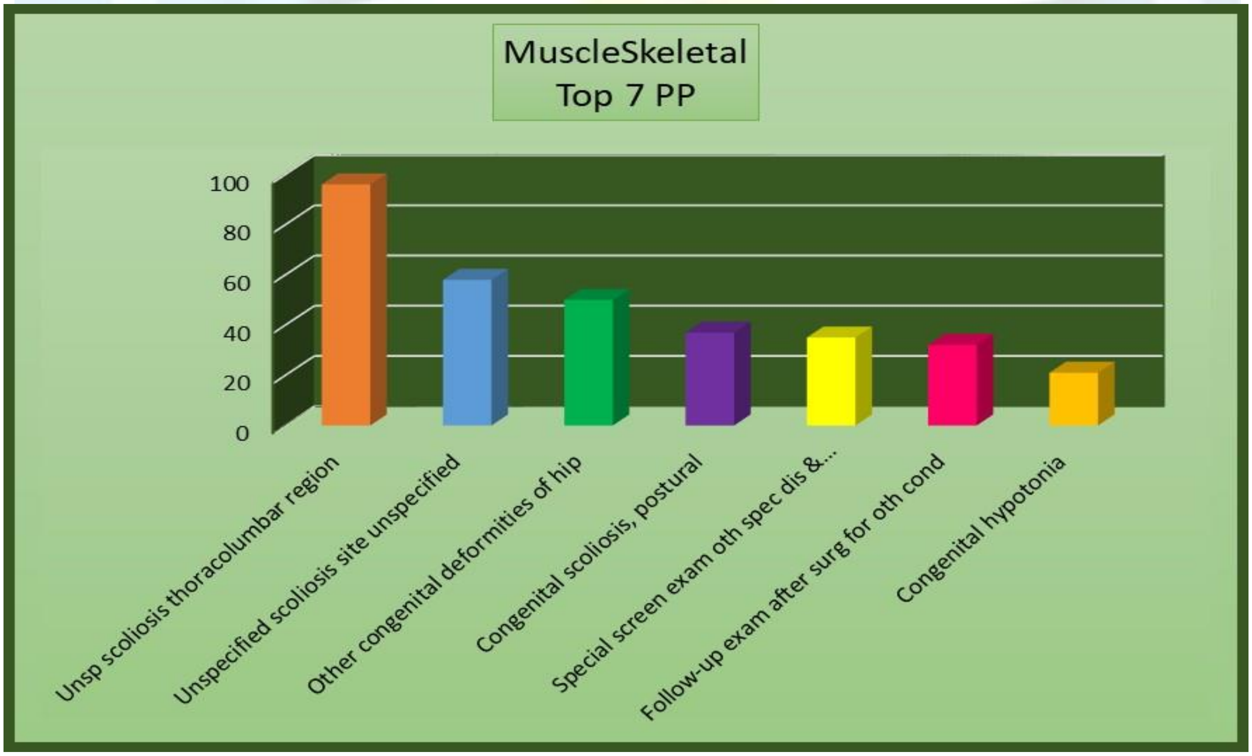


Figure 4-7 Musculoskeletal Top Seven Presenting Problems

The seventh category Infection (n=816) is comprises 166 infection-related codes with the Top Four presenting problems detailed in the following Figure 4.8.

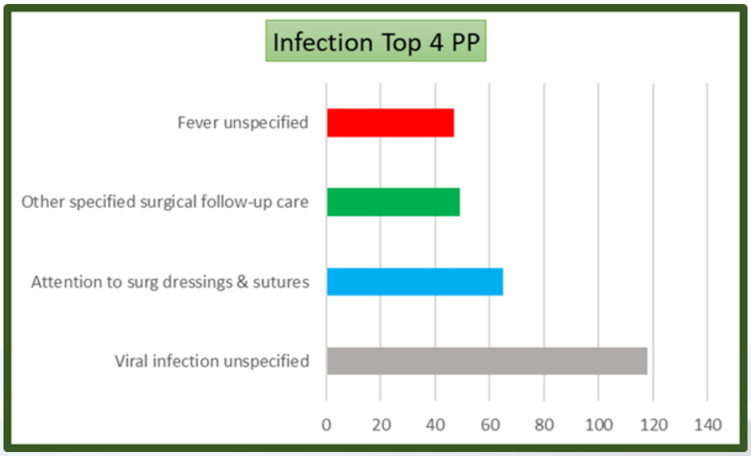


Figure 4-8 Infection Top Four presenting problems

Sleep (n=574), the eighth category, comprises 11 sleep-related codes with the Top Four presenting problems detailed in the following Figure 4.9.

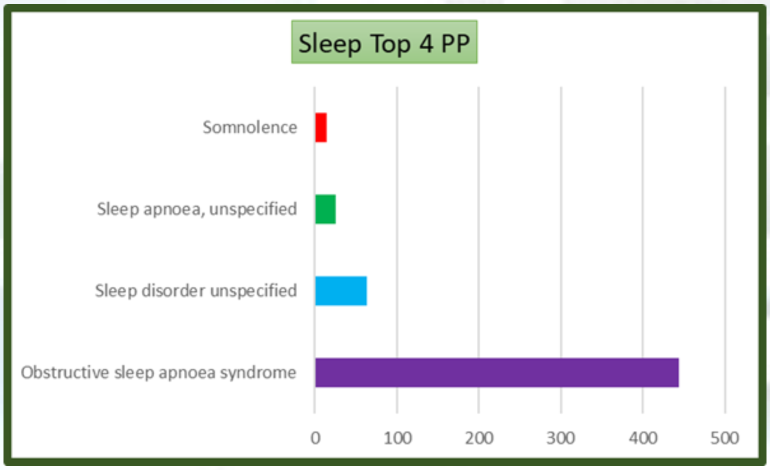


Figure 4-9 Sleep Top Four presenting problems

Renal (n=498), the ninth category, contained 41 renal-related codes with the Top Four presenting problems detailed in Figure 4.10.

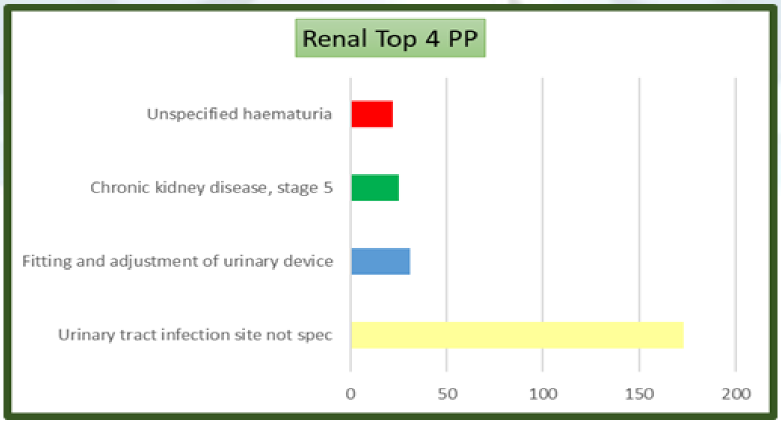


Figure 4-10 Renal Top Four presenting problems

Endocrine (n=471) the tenth category contained 53 endocrine-related codes with the Top Four presenting problems detailed in the following Figure 4.11.

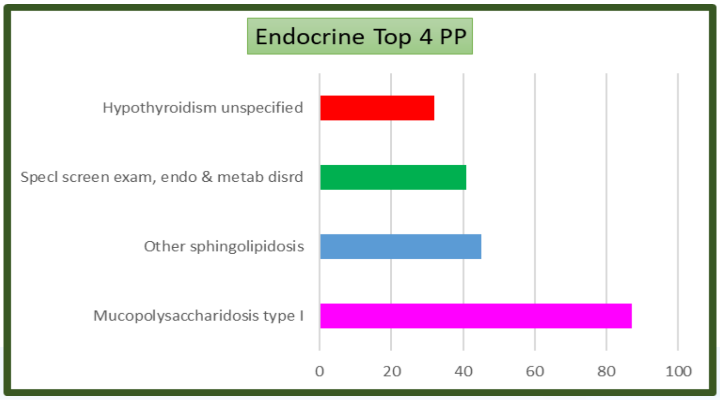


Figure 4-11 Endocrine Top Four presenting problems

Cancer (n=351) the eleventh category contained 79 cancer-related conditions with the with the Top Four presenting problems detailed in Figure 4.12.

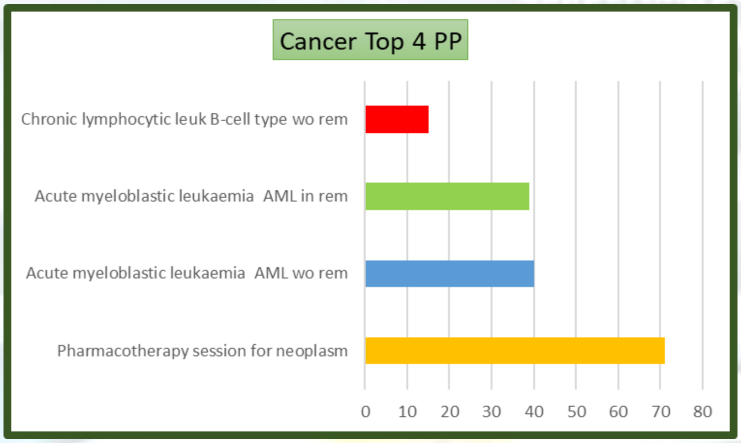


Figure 4-12 Cancer Top Four presenting problems

Haematology (n= 231) the twelfth category represents 54 codes related to haematological presentations with the Top Four presenting problems detailed in Figure 4.13.

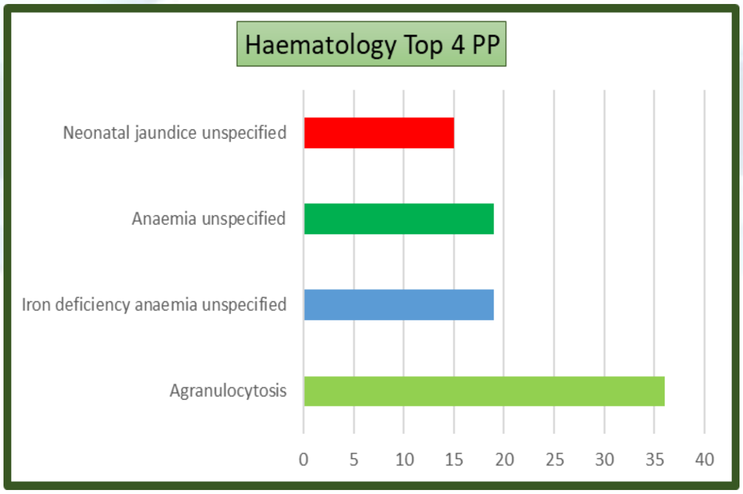


Figure 4-13 Haematology Top Four presenting problems

The final four categories are:

Pain (n=221) with 22 pain-related codes	**Reproductive** (n=167) with 45 reproductive-related codes	**Mental health and behaviour** (n=119) with 33 related codes	**Others** (n=691) with 65 conditions/codes

4.1.4 Admissions characteristics

Length of stay accounted for '104 481' days for the total population, averaging as 6.15 days per admission. Emergency admissions/readmissions accounted for 60.4% (n=63177.5) days. The longest length of stay was 851 days by a 6-year-old boy with a chromosomal condition, admitted because of pneumonitis due to food and vomit inhalation. Table 4.9 identifies the length of stay in total days per type of admission.

Table 4.9 Length of stay in total days per type of admission

Type of admission	**Sum of LOS total**	**Percentage**
Emergency	60705.0	58.0
Elective	24406.5	23.3
New-born	14715.5	14.1
Emergency readmission	2472.5	2.4
Elective readmission	2251.0	2.1
Maternity	130.5	0.1
Grand Total	**104681**	**100**

The majority of 13537 (79.6%) people admitted were discharged under one week's duration (up to six days). A further 11% were discharged prior to day fourteen, accounting for 90.6% of the total population admitted. The remaining 9.3% were admitted for longer than 2 weeks with 96 people admitted for longer than 100 days (Table 4.10).

Table 4.10 Length of stay in days

Length of stay		
100+ Days	96	0.6
60–100 Days	117	0.7
30–59 Days	329	1.9
14–29 Days	1039	6.1
7–13	1869	11.0
0–6 Days	13537	79.6
Total	**16987**	**99.9**
Missing data	11	0.0
Total	**16998**	**100**

From a hospital perspective, the top admitting hospital also had the top length of stay in total days. In contrast, Tallaght Children's Hospital, which was in the Top Five admitting hospitals, had the fifteenth highest length of stay days (Table 4.11).

Table 4.11 Length of stay per hospital

Hospital	**Sum of LOS total**	**Hospital**	**Sum of LOS total**	**Hospital**	**Sum of LOS total**
CHI at Crumlin	30462.5	NMH Holles St	1413.5	Mallow	308.5
CHI at Temple St	12620	St Vincent's UH	1350.5	Tullamore	281
Cork UH	10980.5	Letterkenny UH	1337	Roscommon UH	221.5
Galway UH	6389.5	Cavan	1125.5	St John's	212.5
Beaumont	3820	Wexford	1119	Nenagh	165
Tallaght – Adults	3315.5	Portiuncula UH	1095.5	St Columcille's	153
UH Limerick	3027	Coombe UH	1057.5	Bantry	113
St James's	2753	Rotunda	961.5	Royal Vic EandE	94.5
OLOL Drogheda	2549	Mullingar	915	Ennis	67.5
Mayo UH	2230.5	Mercy UH	876.5	Cappagh	35.5
UH Waterford	2046	Portlaoise	711.5	St Michael's	31.5
Mater UH	1940.5	Limerick UMH	707	Croom	21.5
Sligo UH	1940	Connolly	629.5	St Joseph's Raheny	1.5
St Luke's Kilkenny	1573.5	South Tipperary	500.5	Louth	1.5
CHI at Tallaght	1469.5	St Infirmary VUH	315.5	SLRON Rathgar	1
UH Kerry	1429	Navan	310.5	**Total**	**104681**

Within the 5-year period there were 1640 readmissions within 30 days as detailed in Column S (Readm <30d (Y/N)) and the Top Five reasons for readmission were respiratory, neurological, gastrointestinal, infection, and cardiac-related (table 4.12). 70.3% of people readmitted to hospital (n=1160) were children and 29.7% (n=480) were adults. Table 4. 12 outlines the readmission rates in relation to the presenting problems.

Table 4.12 Readmission reasons

Category	Number
Respiratory	520
Neurological	295
Gastrointestinal (including teeth)	224
Infection	156
Cardiac	85
Renal	65
Musculoskeletal and integumentary system	36
Endocrine	30
Ear nose throat and ophthalmology	24
Haematology	24
Cancer	21
Mental health and behaviour	10
Sleep	3
Reproductive	3
Total PP identified	**1496**
Outliers	111
Intellectual Disability inputted as opposed to PP	33
Total	**1640**

4.1.5 Secondary conditions

Within the 5-year period examined, of the 16998 people with an ID admitted to acute hospitals, there were 32889 secondary conditions listed. The Top Five secondary conditions categories were cardiac, gastrointestinal, neurological, respiratory, and infection-related (Table 4.13).

Table 4.13 Secondary conditions

Category	Number
Cardiac	4565
Gastrointestinal (including teeth)	2910
Neurological	2569
Respiratory	2477
Infection	2104
Musculoskeletal and integumentary system	1627
Renal	1330
Haematology	1317
Ear nose throat and ophthalmology	1246
Endocrine	1213
Mental health and behaviour	865
Sleep	564
Reproductive	239
Cancer	115
Total PP identified	**23141**
Other / Outliers	9748
Total	**32889**

4.2 Chapter Summary

This chapter presents the findings of hospital admission for people with intellectual disability based on the dataset from the NQAIS clinical database for the years 2016 to 2020. The findings, Tables and Figures report the profile of admission, type of admission, presenting problem/s, and hospital stay/readmission.

5. Chapter Five: Discussion

5.0 Introduction

The findings presented the first analysis of the NQAIS clinical dataset pertaining to hospital admissions of people with Intellectual Disability in the RoI from 2016–2020. The discussion will draw on the literature reviewed in Chapter Two and the findings presented in Chapter Four which contextualise the results in context of those who experienced the hospital admissions. Focal points for discussion are first, trends in admission profiles and secondly, possible solutions to reducing hospital admissions.

5.1 Trends in Admission Profiles

This research is timely since, over the past 30 years policy, legislation and advocacy groups have aspired to ensure that mainstream public services support all people and particularly those with disabilities. The Sláintecare implementation plan published in 2018 states that the successful implementation of the Sláintecare vision will require robust knowledge and information drawing on good quality, timely and relevant data sources.

Capturing the presenting problems of people admitted to acute hospitals from 2016–2020 is an important advancement in our understanding of the health needs, patterns of health service utilisation and priority needs of people with an ID in Ireland. Constant research and review comparable to international best practice to identify the causation and need for hospital admission is pertinent to meeting people's health needs.

The data identified most frequent hospital admissions related to respiratory, gastrointestinal, neurological, cardiac, ear/nose/throat/eyes, musculoskeletal, and infections. These conditions match international trends where disorders of the respiratory, gastrointestinal tract and nervous system were identified as the most common cause of hospitalisation of people with an ID (Iacono *et al.* 2020, Axmon *et al.* 2019 and Hand *et al.* 2019a).

It would be remiss not to acknowledge how the COVID-19 pandemic has affected hospital care and delivery in the past year and a half. COVID-19 was evident as the presenting problem in nine cases, of which five cases resulted in death. Within the secondary conditions categorised, COVID-19 was reported/documented as a concern in 175 cases. This number is low considering that people with an ID are especially vulnerable to higher co-morbidities, more severe health outcomes and higher rates of mortality when compared with the non-ID population (Landes *et al.* 2020; Schuengel *et al.* 2020; Turk *et al.* 2020).

Landes *et al.* (2021) identifies that people with an ID had a higher case-fatality rate of COVID-19 and states that data need to be evident and available as there is a paucity of data on COVID-19 among people with ID. One explanation, however, may be that ID services had a lower-case rate. Another explanation could be that some people with an ID infected by the virus may have remained within the disability service and have been supported by paid professionals thus negating the need for hospital treatment. Furthermore, those with Covid-19m who presented to acute services and not admitted as in-patients, were not captured within the NQAIS.

The high prevalence of mental health illnesses and behavioural disorders within the ID population is well articulated within the international literature (Gobrial 2019, Hughes-McCormack *et al.* 2017). However, minimum numbers are evident in this dataset (n=119). This may be representative of the fact that the NQAIS clinical dataset comprises only the acute hospital admissions and does not capture the ED admissions of acute mental health admissions. In the RoI, psychiatric admissions and discharges to in-patient psychiatric services are recorded on the National Psychiatric In-Patient Reporting System (NPIRS) maintained by the HRB and not by the NQAIS clinical dataset as used for this study.

The total death figure of 289 identified in the five-year period within the data and accounts for 1.7% of the population admitted for the years 2016–2020. This equates to approximately 59 deaths *per annum* in hospitals across the lifespan for people with an ID reported within the NQAIS clinical dataset. The National Office of Clinical Audit may be interested in reviewing these data and continue to monitor this figure for future Audits of Hospital Mortality.

Similar to McMahon and Hatton (2021), our findings report that people with an ID have lower incidence of cancers than the general population. However, there is substantial variation in the prevalence rates of major health problems for people with an ID reported across different studies and how they compare to people without ID. Methodological reasons for this principally focus on inconsistent definitions of intellectual disability, diverse diagnostic tools and small sample sizes used in studies (McMahon and Hatton 2021).

5.1.1 Gender

The Central Statistics Office (CSO 2016) note a higher ratio of ID in males than females with a ratio of 1.6:1 which is similar to international reports (Lindgren *et al.* 2021, Iacono *et al.* 2020). This correlates to registrations with NASS of 9826 males (56.2%) and 7655 females (43.8%) with an intellectual disability (Casey *et al.* 2020). The findings of this study identify male admissions of 53% (n=9007) compared with female admissions of 47% (n=7991).

5.1.2 Children

From an age perspective, 24% (n=4204) of NASS registrants are children with ID aged from 0–17 years of age, (Casey *et al.* 2020). Children aged from 0–17 years of age accounted for 74.5% of hospital admissions in this research. While the child population accounts for a higher percentage of admissions internationally (Amor-Salamanca and Menchon 2018) a significant percentage of the sample of this study (45.3%) were in the 0–5 age group. This may reflect how sustaining life in infancy has become more achievable with premature babies with complex needs now more likely to live into adulthood, experiencing many health issues earlier which most often continue throughout life.

Within the public acute sector, there is a range of specialist and general hospitals. Given the number of children represented within this research it is not surprising that the three children’s hospitals appear in the Top Five admitting hospitals and accounted for 42.9% (n=7298) of all admissions.

This high representation of children within the dataset is expected, noting the model of service provision where these hospitals are ‘children specific’ acute hospitals which provide a range of specialist services, treatments and child specialists’ onsite in comparison with small children’s units, attached to larger acute hospitals. This raises the question as to whether children with ID in the RoI are presenting with greater health and or complex health needs (Brennan *et al.* 2021) or are children more likely to be admitted (Dunn *et al.* 2018) due to a more specialised developed paediatric service?

It may not be feasible to have ‘centres of excellence’ or children’s hospitals throughout Ireland. However, there is a clear need to explore and examine how we can support these children and their families in light of the commitment within the UNCRPD to provide “*health services as close as possible to people’s own communities, including in rural areas*”. While specialised paediatric service and ‘Centres for Excellence’ are welcome, additional challenges in accessing healthcare exist for family carers, parents and legal guardians living beyond the Dublin region.

Within the data, LOS averaged at 6.15 days and the top admitting hospitals had longer LOS. This correlates with the numbers of children with ID admitted to the larger children specialised hospitals rather than local children’s units within local acute hospitals. The 6.15 days average identified within the analysis compares with international literature reports ranging from 3.5 days (Glover *et al.* 2020), 3.9 to 7.7 days (Chenbhanich *et al.* 2019), 4.9 days (McDermott *et al.* 2018a) 8.5 days (Domínguez-Berjón *et al.* 2018) and 3.8 days (Fitzgerald *et al.* 2013) for people with an ID admitted to an acute hospital.

However, as children travel to these centres of excellence in Dublin the average LOS may be increased in an effort to prevent readmission. However, complexity and level of needs are not possible to correlate as ‘level of disability’ is not coded within the NQAIS clinical dataset.

When comparing bed-days used by the general population for emergency and elective hospital attendance (Figure 5.1), based on the findings of this study, it appears that the ID cohort as a group ‘buck this trend’. This is apparent. as the latest statistics in 2018 (GoI 2020), identify those aged 65 years as highest bed-days occupants while this study highlights the 0–19 ID age groupings occupancy trend differs from the national general population data.

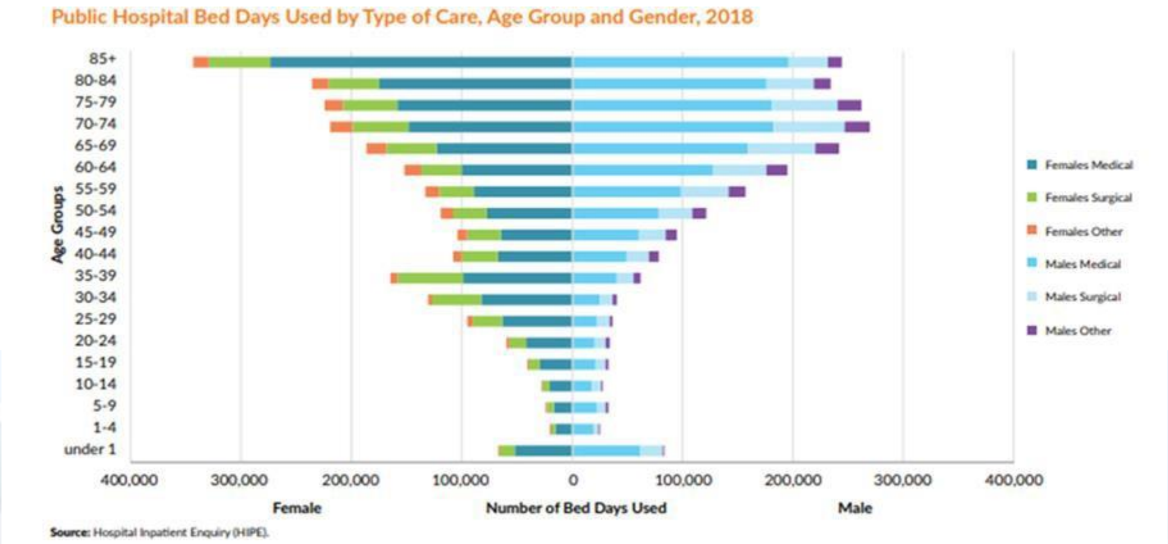


Figure 5-1 Public Hospital Bed-Days Used by Admission Type, Age Group and Gender, 2018

5.1.3 Adults

Adults (n=13277) account for 76% of all NASS registrants (Casey *et al.* 2020) and the number of hospital admissions for adults, accounted for with an ID, was 25.6% (n=3642) within the NQAIS clinical dataset. It is clear to see the reversal in comparison with children's' admissions and that of the general adult public. Modernisation of community-based disability services in line with national and international policies, advocating for non-admission to residential care is reflective of the study residence status data and the NASS data where 67% (n=15110) of people with an ID reside within a family setting and 24.2% (n=5419) within residential care (Casey *et al.* 2020). Of those in residential care, 5010 (95%) reported an ID as their primary disability and 4299 (81%) were aged ≥ 40 years.

There were 3642 adult hospital admissions reported in this study, which is somewhat lower than anticipated and could be due to the adult population with an ID living in residential or supported accommodation and not frequenting acute services due to:

- Preventive and screening processes averting or avoiding development or progression of illnesses and management of conditions overseen in residential or supported accommodation by paid professionals; and
- Adults not admitted to hospital and discharged through Emergency Departments if resident within a disability service. The discharge profile of this study found that 3.6% (n=619) of all discharges were to nursing home, convalescent home or long stay accommodation.

In addition, the dataset revealed, in the ‘Other Category’, some outliers such as the reason for hospital admission reported by coders as ‘holiday relief care’ (25 admission and 11 readmissions). This seems completely at odds with the role of acute services and any sense of holiday experience for an individual. This is perhaps indicative of the lack of respite care and support for families across the lifespan (Kelly *et al.* 2020; Nicholson *et al.* 2019), nevertheless inappropriate for both the service and the individual. To address the lack of respite care and planning for care facilitation of ‘future plans’ with people with an ID and their families is warranted (Dew *et al.* 2019; Burke *et al.* 2018).

The research also found that ‘admission and readmission within 30 days’ demonstrates inaccuracies in relation to the coding process. This study identified that 10.7% (n=1994) entries were coded with ICD-10 code for an ID condition as the ‘primary presenting’ problem rather than a medical condition or follow-up care interventions. This requires attention by coders and healthcare professionals recording case notes as ID in itself should not be a reason for hospital admission.

5.2 Possible Solutions to Reducing Hospital Admissions

The ‘top presenting problems’ identified in the Findings Chapter reflect conditions similar to those identifies by Balogh *et al.*, (2011) and Purdy *et al.*, (2009) as conditions with potential to offer improved health outcomes and a reduction in hospital admissions for people with ID, if timely and effective outpatient care is provided (Table 5.1). These Ambulatory Care-Sensitive conditions purport to reduce the risks of hospitalisation by either preventing the onset of an illness or condition, controlling an acute episodic illness or condition, or managing a chronic disease at the primary level (Hand *et al.* 2019a; McDermott *et al.* 2018a).

Table 5.1 Ambulatory care-sensitive conditions specific to people with ID

Balogh *et al.*, (2011) Canada	**Purdy *et al.*, (2009) NHS England**
1. Asthma,	1. Influenza and pneumonia
2. Angina pectoris	2. Other vaccine-preventable conditions
3. Congestive heart failure	3. Asthma
4. Gastrointestinal ulcer	4. Congestive heart failure
5. Immunisation preventable infection	5. Diabetes complications
6. Malignant hypertension	6. Chronic obstructive pulmonary disease
7. Otitis media	7. Angina
8. Anxiety	8. Iron deficiency anaemia
9. Dental conditions	9. Hypertension
10. Diabetes	10. Nutritional deficiencies
11. Pelvic inflammatory disease	11. Dehydration and gastroenteritis
12. Constipation	12. Pyelonephritis
13. Gastroesophageal reflux	13. Perforated/bleeding ulcer
14. Epilepsy	14. Cellulitis
15. Schizophrenic disorders	15. Inflammatory disease
	16. Ear, nose and throat infections
	17. Epilepsy conditions
	18. Gangrene

However, addressing admission and readmission for people with an ID is not without its challenges. One means of supporting this agenda would be the provision of RNID Clinical Nurse Specialists (CNS) and RNID Advanced Nurse Practitioners (ANP) as key professionals with specific education and clinical expertise in disability.

The report *Shaping the Future of Intellectual Disability Nursing in Ireland* (McCarron *et al.* 2018) highlights the health promotion and health facilitation role of the RNID when caring for the person with an ID across the lifespan and recommends that the RNID be situated as ‘the point of contact’ within all healthcare services. This study’s dataset can assist in further decision-making and service planning, endorsing integration of the RNID within mainstream health and social services across primary care, tertiary, acute services, and mental health services.

Development/expansion of the existing RNID role is in line with international trends in service design and the provision of community nursing roles, liaison roles and consultant roles (Brown *et al.* 2016). In particular, consideration of CNS and ANP development in clinical areas identified as treating the top presenting problems for hospital admissions *i.e.*, respiratory, gastro-intestinal and neurological is warranted.

CNSs and ANPs aim to integrate community- and primary-level care in meeting the needs of the population by providing health education and promotion along with the exploration of public health strategies, lifestyle choices, early diagnosis, and the identification of potential interventions for preventable causes of diseases (Chang *et al.* 2017). The value of the CNSs in intellectual disability nursing is recognised and valued (Doody *et al.* 2019; Doody *et al.* 2018; Doody *et al.* 2017a; Doody *et al.* 2017b). ANPs are highly skilled and experienced experts in clinical practice who provide complete episodes of care in response to an individual’s needs which include assessments, examinations, diagnostics, medication prescribing, referral, and follow-up care.

ANPs have a positive impact for patients and services (McDonnell *et al.* 2015) as seen through reducing waiting lists on average 3.9 patients per week with an average 4.3 patients per ANP avoiding hospital admission on a weekly basis. A reduction of up to 2 hours 43 minutes in overall Patient Experience Times (PET) for patients seen in emergency care areas which include ANPs as part of the care delivery model and a positive patient experience has been reported (HSE 2020; McDonnell *et al.* 2015).

While the narrative experiences of people with an ID where not reflected in the NQAIS clinical dataset, clear evidence from the reviewed literature highlights some pertinent points worth including in the discussion. Experiences of hospital services for people with an ID are acknowledged as fearful encounters, often with an overreliance on family carers during the entirety of stays together with problem attitudes and limited knowledge of hospital staff sometimes resulting in dire outcomes. As already discussed, recommendations to ameliorate problems include developing liaison models, especially through a disability liaison nurse, supporting carers and improving communication within healthcare settings.

In addition, the specialist knowledge and clinical experience of RNID’s may address the ‘quandary’ of concerns relating to communication barriers and lack of relevant background information often reported by medical and adult/children’s nurses when caring for people with an ID (Howie *et al.* 2021; Appelgren *et al.* 2018). Many acute hospital staff have indicated over the years that caring for people with an ID requires significant time and effort; that it can be extremely difficult to obtain consent and that they lack knowledge of the ID population (Sowney and Barr 2007).

Addressing these issues requires consideration of the RNID skillset within acute services in order to promote effective and inclusive communication plus interventions such as Health Passports and technological apps to promote integration within and across services warrant consideration and actioning. '*Continuing education for all healthcare professionals would address knowledge, attitudes, misconceptions and practical supports ensuring safe, quality care delivery promoting inclusive communication and rights based person-centred care'* (Metcalf and Colgate 2019; Auberry 2018).

5.2 Limitations

This study is a welcome addition to the existing ID health and social data available in Ireland and while it is evident that people with an ID are frequent users of general hospital in-patient services for a wide range of physical and psychological conditions, the NQAIS clinical system may have omissions which affect the generalisability of the study findings.

First, we must recognise that, while the data presented in the findings are representative of the ID population, it was not possible to categorise the level of disability. Thereby, it is not possible to identify if all levels of ID (mild, moderate, severe, and profound) are represented in the data or if any category is over- or under-represented. Thus, we express caution with regards to the interpretation and generalisability of the research findings.

Secondly, the findings present the first physical health dataset of people with an ID in Ireland. Further work and analysis would be necessary to identify the intersection between variables including, for example, age profile, level of disability, and the number of co-existing conditions. Furthermore, epidemiological analysis was not possible within the 12-week period of the study, but it is a recommendation that an annual or biannual report would include comparable population statistics of age, gender, presenting problems, length of stay, *etc.*

Thirdly, while the study findings are an accurate account of hospital admissions for people with evident causes such as Down Syndrome, the findings may not be representative of all people with ID. For example, those with a mild ID are not always identified. Therefore, the data on the system may be incomplete. In addition, disability should be recorded in the diagnosis-related classification (Dx 2-30 ICD code) section, but it is unclear as to how this diagnosis is gained and hospital staff may miss this classification/diagnosis due to the difficulties in identifying mild ID or specific ID conditions (McDermott *et al.* 2018b; Krahn *et al.* 2010). In addition, the under-representation of certain conditions due to undiagnosed conditions or the 'hidden majority' such as adults with a mild ID and those who do not access ID services (Emerson *et al.* 2016; Emerson and Hatton 2014) cannot be underestimated.

Fourthly, the data are only representative of admission to acute care within the hospital and does not include ED admissions or acute psychiatric admissions. As ED admission and discharges are not recorded in the data system, the true nature of the presenting problems may not be fully represented especially given the possibility that one third of people with an ID were discharged back to their support service without admission.

This is evident in the national statistics where. for instance, the NASS reports 22 434 people with an ID (Casey *et al.* 2020) and the 2016 census identifies 35470 people with an ID across all ages in Ireland (CSO 2016). This discrepancy arises in how data are gathered, how ID is defined and criteria for registration within different registers (Doody and Doody 2012). Here, a broader concern for consideration relates as to how ID is defined and whether an assessment and diagnosis is needed *versus* a person or a family member defining themselves as having an ID and a registration based on receipt or registered for services (Bruton *et al.* 2020).

5.3 Chapter Summary

Understanding the frequency and types of admissions of people with an ID experience can provide us with the knowledge to inform where and how to focus support for primary, secondary, and tertiary care now and in the coming years. This focus would allow us to develop appropriate and responsive healthcare services focusing on health promotion, health education and health management. This is important given the fact many people with an ID within the population have additional needs and more physical conditions which can result in more frequent hospital admissions (Cooper *et al.* 2018). While health and social care service models are responsive to ensuring person-centred approaches, there is still a need and a challenge for modern healthcare services to focus on individualised support, self-determination, evidence-based practice, and effective team working (Doody *et al.* 2021).

Health data are essential in planning and directing policy and services and this research offers some suggestions to contribute to this decision-making and service planning. Provision of Ambulatory Care-Sensitive conditions and services, in primary and community levels, are two suggestions arising from this study and which are aligned to current national and international policies.

6. Chapter Six: Conclusions and Recommendations

6.0 Introduction

This chapter provides a summary of the conclusions of this first dataset analysis of acute hospital admissions specific to ID in Ireland based on the NQAIS clinical dataset. Recommendations are made based on the findings and discussion and are applicable to healthcare provision, practice, education, policy, and research.

6.1 Conclusions

The findings of this analysis of NQAIS clinical data in Ireland draws similarity to international evidence for presenting problems for people with ID, suggesting that the findings are broadly generalisable. Overall, the significant role of the NQAIS clinical database and presentation of the HIPE data for acute hospitals in Ireland cannot be underestimated. However, consideration needs to be given to ensure that all essential data are captured, and that there is consistency in reporting and terminology, standardisation, and interconnectivity of national datasets. The NQAIS clinical database has a role to play in the improvement of quality service planning and the implementation of a person-centred infrastructure of healthcare provision tailored to meet the individual needs of people with an ID and their families.

However, this dataset does not capture ED or mental health admissions. Recording issues are evident within the dataset. Issues related to coding of primary and secondary conditions and the level of disability raises the question whether we should capture the level of disability in the coding and other medical or nursing documentation. Ensuring annual or biannual data reviews would aid the population with an ID and the timely and appropriate service planning towards improvements in the coming years as we refocus resources and services in disability reform. This is a critical juncture to ensure that databases and research dissemination is facilitated in order to enable service planning to meet the needs of people with an ID and their families aiming to lead to improvements in health, well-being, and reduction of health disparities.

Reducing disparities and addressing social drivers of health in order to improve the health outcomes of people with an ID requires systemic change. The evolving role of the RNID is pivotal to driving this systemic change for and in conjunction with people with an ID and their families.

As presenting problems and risks differ for people with ID, health assessment and screening need to be addressed through health promotion, health education and illness prevention to target these specific and unique risks. Maintenance of health must encompass a multidimensional and multidisciplinary approach to improve outcomes and standards for care. There is a need to develop and support specialist and advanced nursing roles within the multidisciplinary team to guide, support and plan for the complexity in person centred service provision for people with ID. In addition, there is a need to support services and its leaders to enable people with an ID experience significant improvements in the care provided (Doody *et al.* 2021) to ensure a transformation of services into human services which are focussed on fulfilling person-centred outcomes (Jukes and Aspinall 2015).

Providing high quality personalised care can be a challenge and requires investment and engagement to develop health and social care leaders in ID in order to demonstrate their skills so as to effect change service provision, to engage clients/service users/family members in their care planning and to embed person-centred care across the health and social care system (Doody *et al.* 2021). The RNID can be a leader in driving systemic change for people with an ID. Thus, it is important to promote the field of ID care and recognise and celebrate the contribution ID nurses make through consulting, liaising and role modelling to exert their influence across the healthcare communities and tackle the institutionalised discrimination experienced by vulnerable groups.

This integration and inclusion of ID nurses in specialist and advanced practice roles will assist in addressing issues reported by healthcare professions where they report to feeling ill equipped and prepared to care for people with an ID due to communication barriers and lack of specific knowledge (Lunsky *et al.* 2014).

Internationally healthcare professionals experience challenges when providing healthcare to people with ID. Consideration needs to be given to the educational needs of healthcare professionals to enhance the provision of healthcare for people with ID. Electronic means such as webinars and online workshops can be utilised to support the educational needs of the healthcare professional in becoming confident and competent in using various tools of assessment, diagnosis and communication. To support the communication between healthcare professionals and people with ID, a standardised hospital passport could be implemented across Ireland.

With current advances in technology, telehealth and online tools, these could also be explored and utilised in some healthcare settings. Media is a powerful tool and should be utilised more in the future to promote health equity and communication in a changing landscape of healthcare provision for people with an ID. However, such strategies need to be led, coordinated and supported by nurse specialists (CNS/ANP) as they have the expertise, experience and have a positive impact for patients and services (McDonnell *et al.* 2015).

Within this report readmission occurred for 9.6% (n=1640) of the population with and ID admitted to the acute hospital and like the admission rates, children accounted for a higher proportion 70.3%, compared with 29.7% for adults. In the literature, such presentation may represent bias, diagnostic overshadowing, poor-quality care and failure to conduct appropriate diagnostic assessments. This is referred to as 'ambulatory care-sensitive conditions' or conditions, which if managed effectively at the primary care level, would avoid a hospital admission (Hodgson *et al.* 2019).

While the NQAIS clinical database provides clear data, there is a need for greater understanding and integration of all health datasets to characterise the true pattern of health service use among people with ID. This could contribute to reduce health inequalities, improve coordination of care and long-term health conditions, and in turn reduce the risk of premature death (Chang *et al.* 2017). Furthermore, greater attention, awareness and support for the health promotion and health education needs of people with an ID and their immediate carers must be addressed to promote self-care, empowerment and improved health.

Consequently, involving people with an ID and family carer in service planning, development and evaluation are necessary as such people are the experts in their own lives. This would support an enhanced quality of life (Heifetz and Lunsky 2018). In addition to hospital presentation, the cause of death for people with an ID needs to be monitored. Strategies supporting disease prevention and complications in people with an ID and to reduce the risk of premature death (Brameld *et al.* 2018) is necessary.

While Ireland has made great strides to improve service provision for people with an ID and there is a clear trajectory favouring the development of community-based services. This has clear implications for the person-centred infrastructure within the acute hospital setting. Skilled ID nurses need to be operational across all health services people with an ID use (McCarron *et al.* 2018). National policies support the development of community-based services, also consider support required by families.

Therefore, there is a need for a community-based role and clinics in supporting and planning with the person with ID and their families. Accessing health and social care services can present many challenges. There is a clear need for a link-person to support the care delivery process for the person with ID, so as to promote access and reduce the existing identified gaps. The experienced RNID has a fundamental role in actively implementing service reform, facilitating person centred care and assisting decision-making.

Considering the high medical support needs across the lifespan for people with an ID, there is a requirement for specialist nursing support and addressing service gaps. Based on the findings of this report, there seems to be a deficit in relation to the provision of respite care, support for families across the lifespan and geographical issues which may be affecting length of stay due to the location of children hospitals. Furthermore, to promote a seamless service, there is a need to incorporate the needs of people with ID, ensuring ICD codes/coding and professional documentation within the curriculum and in the educational preparation of all healthcare and social care professionals.

6.2 Recommendations

Based on the analysis of the NQAIS clinical dataset, there are several recommendations addressing healthcare provision, policy, education and research.

From a healthcare provision perspective, the analysis highlights the need to address support needs of people with an ID and their families and the potential contribution of specialist skill and knowledge of RNIDs within the wider health system. Based on the findings of the analysis the following are proffered:

Healthcare Provision Recommendations

1. Given the extensive health needs, communication difficulties, length of hospital stay and use of centres of excellence, the necessity to explore and implement 'patient and family-centred care' (PFCC) approaches within acute services is warranted in order for individuals with ID to achieve best health outcomes.
2. Contribution of Family Carers when accessing and engaging with acute health servicesrequires recognition of their role as supporter, communicator and health facilitator.
3. Appropriate healthcare requires inclusive approaches for communication to be timely, accessible and respectful. Technology such as telehealth and video consultations are recommended, in lieu of face to face consultations for people living long distances from 'centres of excellences' or for those with transport difficulties and other responsibilities.
4. Promotion of '*Health Passports*' is recommended to support healthcare staff to understand the '*complexity of need'* and the '*intersection of support'* required by people with intellectualdisabilities in order to achieve improved health outcomes. Referral of people with an ID without a health passport to a community or liaison RNID to establish a health passport is recommended.
5. This study recommends advancing the RNID community- and liaison-practice role to support the health needs of people with an ID and in particular 'health promotion, health prevention and health education' interventions through a PFCC model.
6. The study identifies the need and priority areas for the development of advanced and specialist RNID posts to support people with the Top Five presenting problems of respiratory, gastrointestinal, neurological, cardiac, and ear nose throat and eyes symptoms/illnesses.
7. In line with national policy the integration of RNIDs within community, liaison, advanced practice and consultancy roles should occur to support the multidimensional and multidisciplinary service approach required for people with an ID and their families.

From a practice perspective, the inputting of data and coding are key issues which would support recording and analysis and the following recommendations proffered

Practice Recommendations

1. To aid comparison, decision-making and service planning, an annual review of the profile of admissions of people with an ID to hospital within the NQAIS dataset is required.
2. Clear guidance and agreement for inputting data is required regarding intellectual disability codes. ID codes should not be inputted as the 'presentation problem' or 'cause of death'.
3. The feasibility of recording the 'level of disability' needs to be considered as it should be incorporated into data collection and data coding to assist identification of needs based on complexity.

From an education perspective, the analysis highlights the need for education around ID awareness for healthcare professionals across the multidisciplinary team, health education and health promotion for people with an ID and their families. Based on the findings, the following recommendations for education are proffered

Education Recommendations

1. Education programmes for healthcare professionals addressing communication, assessment, health profile, clinical, and behavioural phenotypes for people with an ID should be implemented.
2. Health promotion programmes specific to people with an ID should be developed prioritising the health profiles evident within this report.
3. Familiarisation of the NQAIS clinical dataset is recommended for health and social care practitioners and educationalists, with particular regard to reporting sections within the NQAIS clinical dataset and ICD codes to enhance understanding, recording, analysis and reporting of clinical data.

From a policy perspective, the analysis highlights the need for an agreed and standardised approach for data gathering and reporting. In addition, consideration to data pertaining to the population profile and linking national programmes and initiatives need to be addressed. Based on these findings, the following recommendations for policy-makers are proffered

Policy Recommendations

1. A standardised national approach should be agreed for data categorisation, noting discrepancies between NASS and other GoI agencies, *e.g.*, age groupings, definition of ID.
2. Data collection should capture the full presentation and profile of people with an ID thus integrating ED and mental health admissions information.
3. An annual or biannual report addressing the full profile of presentation, health issues and causes of death in people with an ID is recommended to allow for robust monitoring, tracking, evaluation of health(care) information, and outcomes.

From a research perspective, this report highlights the value of the NQAIS clinical database in identifying the acute admission health needs of people with ID. This dataset could be utilised to identify the full profiles of certain conditions and comparability to other group or the general population. Based on the analysis the following recommendations are made for future research:

Future Research Recommendations

1. Future research should be conducted to identify specific issues pertaining to specific conditions, age groups, level of disability, and length of stay.
2. A comparison of the health profile of people with an ID as compared with the general population should be conducted.
3. Further analysis on 2020/2021 COVID-19 data and outcomes needs to be conducted.
4. This research needs to be reinforced by capturing clients/service users and families' perspectives on health, healthcare access, healthcare utilisation and experiences within acute care.
5. Additional research is required to examine over time the cost benefit analyse of any intervention or strategies implemented to support the healthcare needs of people with ID.

6.3 Chapter Summary

This chapter concludes the project by synthesising the contribution of the project and articulating recommendations aiming to support future decision-making and service planning for the enhancement of effective, safe and quality care for people with ID, their families and support networks.

References

Abdullahi I., Wong K., De Klerk N., Mutch R., Glasson E.J., Downs J., Cherian S., Leonard H. (2020). Hospital admissions in children with developmental disabilities from ethnic minority backgrounds. *Developmental Medicine and Child Neurology*. 62(4):470-476.

Ahlström G., Axmon A., Sandberg M., Flygare Wallén E. (2020) Health care utilisation among older people with Down syndrome compared with specific medical guidelines for health surveillance: A Swedish national register study. *BMC Health Services Research*. 20(1):1-18.

Ailey S.H., Johnson T.J., Fogg L., Friese T.R. (2015). Factors Related to Complications Among Adult Patients with Intellectual Disabilities Hospitalized at an Academic Medical Center. *Intellectual and Developmental Disabilities*. 53(2):114-119.

Ailey S.H., Johnson T., Fogg L., Friese T.R. (2014) Hospitalizations of Adults with Intellectual Disability in Academic Medical Centers. *Intellectual and Developmental Disabilities*. 52(3):187-192.

Amor-Salamanca A., Menchon J.M. (2018) Rate and characteristics of urgent hospitalisation in persons with profound intellectual disabilities compared with general population. *Journal of Intellectual Disability Research*. 62(3):179-186.

Appelgren M., Bahtsevani C., Persson K., Borglin G. (2018) Nurses’ experiences of caring for patients with intellectual developmental disorders: a systematic review using a meta-ethnographic approach. *BMC Nursing*. 17(1):1-19.

Auberry K. (2018) Intellectual and developmental disability nursing: current challenges in the USA. *Nursing Research and Reviews*. 8:23-28.

Axmon A., Björkman M., Ahlström G. (2019) Hospital readmissions among older people with intellectual disability in comparison with the general population. *Journal of Intellectual Disability Research*. 63(6):593-602.

Axmon A., Ekwall A., Ahlstrom G. (2020) Incidents resulting in health care among older people with intellectual disability in comparison with the general population: A national register study. *Journal of Intellectual and Developmental Disability*. 45(2):139-143.

Axmon A., Karlsson B., Ahlström G. (2016) Health care utilisation among older persons with intellectual disability and dementia: a registry study. *Journal of Intellectual Disability Research*. 60(12):1165-1177.

Baek H., Cho M., Kim S., Hwang H., Song M., Yoo S. (2018) Analysis of length of hospital stay using electronic health records: A statistical and data mining approach. *PLoS ONE*. 13(4): e0195901.

Balogh R.S., Ouellette-Kuntz H., Brownell M., Colantonio A. (2011) Ambulatory care sensitive conditions in persons with an intellectual disability–development of a consensus. Journal of Applied Research in Intellectual Disabilities. 24(2):150-158.

Bebbington A., Glasson E., Bourke J., de Klerk N., Leonard H. (2013) Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983–1999: A population-based cohort study. *BMJ Open*. 3: e002356.

Benevides T.W., Carretta H.J., Graves K.Y., Sikka V. (2020) Emergency department use among young adult Medicare beneficiaries with autism and intellectual disabilities. *Research in Autism Spectrum Disorders*. 70:101470.

Blaskowitz M.G., Hernandez B., Scott, P.W. (2019) Predictors of emergency room and hospital utilization among adults with intellectual and developmental disabilities (IDD). *Intellectual and Developmental Disabilities*. 57(2):127-145.

Brameld K., Spilsbury K., Rosenwax L., Leonard H., Semmens J. (2018) Use of health services in the last year of life and cause of death in people with intellectual disability: a retrospective matched cohort study. *BMJ Open*. 8:e020268.

Brown M., Chouliara Z., MacArthur J., McKechanie A., Mack S., Hayes M., Fletcher J. (2016) The perspectives of stakeholders of intellectual disability liaison nurses: A model of compassionate, person-centred care. *Journal of Clinical Nursing*. 25(7-8):972-982.

Bruton L., Gibney S., Collins D. (2020) *Social Impact Assessment Series: Specialist Disability Services for People with Intellectual Disabilities*. Dublin: The Stationery Office.

Burke M., Arnold, C., Owen A. (2018) Identifying the correlates and barriers of future planning among parents of individuals with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*. 56(2):90-100.

Casey C., O'Sullivan M., Fanagan S., Doyle A. (2020) *National Ability Supports System (NASS) 2019*. Dublin : Health Research Board.

Central Statistics Office (2016) *Census of Population 2016 –Profile 9 Health, Disability and Carers*. Dublin: Central Statistics Office.

Chang C.K., Chen C.Y., Broadbent M., Stewart R., O'Hara J. (2017) Hospital admissions for respiratory system diseases in adults with intellectual disabilities in Southeast London: A register-based cohort study. *BMJ Open*. 7:e014846.

Chenbhanich J., Wu A., Phupitakphol T., Atsawarungruangkit A., Treadwell T. (2019) Hospitalisation of adults with Down syndrome: lesson from a 10-year experience from a community hospital. *Journal of Intellectual Disability Research*. 63(3):266-276.

Cooper S.A., Hughes McCormack L., Greenlaw N., McConnachie A., Allan L., Baltzer M., McArthur L., Henderson A., Melville C., McSkimming P., Morrison J. (2018) Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: A population-based cohort study. *Journal of Applied Research in Intellectual Disabilities*. 31:68-81.

Cooper S.A., McLean G., Guthrie B., McConnachie A., Mercer S., Sullivan F., Morrison J. (2015) Multiple physical and mental health comorbidity in adults with intellectual disabilities: Population-based cross-sectional analysis. *BMC Family Practice*. 16(1):110-120.

Cronin P., Ryan F., Coughlan M. (2008) Undertaking a literature review: a step-by-step approach. *British Journal of Nursing*. 17(1):38-43.

Department of Health. (2019a) *A Policy on the Development of Graduate to Advanced Nursing and Midwifery Practic*e. Dublin: The Stationery Office.

Department of Health. (2019b) *National framework and principles for the design of models of care*. Dublin: The Stationery Office.

Department of Health. (2019c) *Sláintecare action plan 2019*. Dublin: The Stationery Office.

Department of Health. (2012) *Value for money and policy review of disability services in Ireland*. Dublin: The Stationery Office.

Department of Health. (1996) *Towards an independent future: the review group on health and personal social services for people with physical and sensory disabilities*. Dublin: The Stationery Office.

Department of Health. (1990) *Needs and abilities: A policy for the intellectually disabled, report of the review group on mental handicap services*. Dublin: The Stationery Office.

Department of Health and Children. (2011) *Report of disability policy review: Expert reference group on disability policy*. Dublin: The Stationery Office.

Department of Health and Children. (2006) *A vision for change. Report of the expert group on mental health policy*. Dublin: The Stationery Office.

Dew A., Collings S., Dillon Savage I., Gentle E., Dowse L. (2019) "Living the life I want": A framework for planning engagement with people with intellectual disability and complex support needs. *Journal of Applied Research in Intellectual Disabilities*. 32(2):401-412.

Disability Rights Commission. (2006) *Equal treatment: Closing the gap. A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems*. London: Disability Rights Commission.

Doody O. (2013) *The contribution and focus of clinical nurse specialists in intellectual disability nursing: an Irish perspective*. Doctoral dissertation, University of Ulster.

Doody O., Carey E., Ryan R., O Halloran M. (2021) *Report on the design, management, and evaluation of a Clinical Leadership Programme for Persons in Charge (PIC) from Intellectual Disability Support Services for Adults and Children in the Republic of Ireland*. Limerick: University of Limerick and National Clinical Leadership Centre for Nursing and Midwifery, HSE.

Doody O., Doody C.M. (2012) Intellectual disability nursing and transcultural care. *British Journal of Nursing*. 21(3):174-180.

Doody O., Slevin E., Taggart L. (2019) A survey of nursing and multidisciplinary team members' perspectives on the perceived contribution of intellectual disability clinical nurse specialists. *Journal of Clinical Nursing*. 28(21-22):3879-3889.

Doody O., Slevin E., Taggart L. (2018) Families' perceptions of the contribution of intellectual disability clinical nurse specialists in Ireland. *Journal of Clinical Nursing*. 27(1-2):e80-e90.

Doody O., Slevin E., Taggart L. (2017a) Focus group interviews examining the contribution of intellectual disability clinical nurse specialists in Ireland. *Journal of Clinical Nursing*. 26(19-20):2964-2975.

Doody O., Slevin E., Taggart L. (2017b) Activities of intellectual disability clinical nurse specialists in Ireland. *Clinical Nurse Specialist* 31(2):89-96.

Doody O., Slevin E., Taggart L. (2012) Intellectual disability nursing in Ireland: identifying its development and future. *Journal of Intellectual Disabilities*. 16(1):7-16.

Dunn K., Hughes McCormack L., Cooper S.A. (2018) Hospital admissions for physical health conditions for people with intellectual disabilities: Systematic review. *Journal of Applied Research in Intellectual Disabilities*. 31:1-10.

Durbin A., Balogh R., Lin E., Wilton A.S., Lunsky Y. (2018) Emergency department use: Common presenting issues and continuity of care for individuals with and without intellectual and developmental disabilities. *Journal of Autism and Developmental Disorders*. 48(10):3542-3550.

Emerson E., Baines S. (2010) *Health inequalities and people with learning disability in the UK: 2010.* Durham: Improving Health and Lives: Learning Disability Observatory.

Emerson E., Baines S., Allerton L., Welch V. (2011) *Health inequalities and people with learning disabilities in the UK: 2011*. Durham: Improving Health and Lives: Learning Disabilities Observatory, England.

Emerson E., Hatton C. (2014) *Health inequalities and people with intellectual disabilities*. Cambridge: Cambridge University Press.

Emerson E., Hatton C., Baines S., Robertson J. (2016) The physical health of British adults with intellectual disability: cross sectional study. *International Journal for Equity in Health*. 15(1):1-9.

Ferrari R. (2015) Writing narrative style literature reviews. *Medical Writing*. 24(4):230-235.

Fitzgerald P., Leonard H., Pikora T.J., Bourke J., Hammond G. (2013) Hospital admissions in children with Down Syndrome: Experience of a population-based cohort followed from birth. *Plos One*. 8(8):e70401.

Glover G., Williams R., Heslop P., Oyinlola J., Grey J. (2017) Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*. 61(1):62-74.

Glover G., Williams R., Oyinlola J. (2020) An observational cohort study of numbers and causes of preventable general hospital admissions in people with and without intellectual disabilities in England. *Journal of Intellectual Disability Research*. 64(5):331-344.

Glover G., Williams R., Tompkins G., Oyinlola J. (2019) An observational study of the use of acute hospital care by people with intellectual disabilities in England. *Journal of Intellectual Disability Research*. 63:85-99.

Gobrial E. (2019) Comorbid mental health disorders in children and young people with intellectual disabilities and autism spectrum disorders. *Advances in Mental Health and Intellectual Disabilities*. 13(5):173-181.

Government of Ireland. (2020) Health in Ireland Key Trends. Dublin: The Stationery Office

Government of Ireland. (2017a) National Disability Inclusion Strategy 2017-2021. Dublin: Government of Ireland.

Government of Ireland. (2017b) Houses of the Oireachtas Committee on the Future of Healthcare: Sláintecare Report. Dublin: Government of Ireland.

Government of Ireland. (2015) *Assisted Decision Making (Capacity) Act*. Dublin: The Stationery Office.

Government of Ireland. (2014) *Human Rights and Equality Act*. Dublin: The Stationery Office.

Government of Ireland. (2007) *Citizens Information Act*. Dublin: The Stationery Office.

Government of Ireland. (2005) *Disability Act 2005*. Dublin: The Stationery Office.

Government of Ireland. (2004) *The disability strategy*. Dublin: The Stationery Office.

Hand B.N., Boan A.D., Bradley C.C., Charles J.M., Carpenter L.A. (2019a) Emergency department utilization and monetary charges in adolescents with autism spectrum disorder, intellectual disability, and a population comparison group. *Autism Research*. 12(7):1129-1138.

Hand B.N., Boan A.D., Bradley C.C., Charles J.M., Carpenter L.A. (2019b) Ambulatory care sensitive admissions in individuals with autism spectrum disorder, intellectual disability, and population controls. *Autism Research*. 12(2):295-302.

Harris J.C. (2006) *Intellectual disability: understanding its development, causes, classification, evaluation, and treatment*. New York: Oxford University Press.

Healthcare Pricing Office (2021) Available at https://www.hpo.ie Accessed 3April 2021.

Health Service Executive. (2020) *Evaluation of the impact of implementing a draft policy to develop Advanced Nurse Practitioners (cANPs/RANPs) to meet health service needs*. Dublin: Health Service Executive.

Health Service Executive. (2018) *A national framework for person centred planning in services for persons with a disability*. Dublin: Health Service Executive.

Health Service Executive. (2012a) *Progressing disability services for children and young people*. Dublin: Health Service Executive.

Health Service Executive. (2012b) *New Directions –Review of HSE day services and implementation plan 2012–-2016: Working Group Report*. Dublin: Health Service Executive.

Health Service Executive. (2011) *Time to move on from congregated settings. a strategy for community inclusion. Report of the working group on congregated settings*. Dublin: Health Service Executive.

Heifetz M., Lunsky Y. (2018) Implementation and evaluation of health passport communication tools in Emergency Departments. *Research in Developmental Disabilities*. 72:23-32.

Heslop P., Blair P., Fleming P., Hoghton M., Marriott A., Russ L. (2013) *Confidential inquiry into premature deaths of people with learning disabilities*. Bristol: Norah Fry Research Centre.

Heslop P., Blair P.S., Fleming P., Hoghton M., Marriott A., Russ L. (2014) The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *The Lancet*. 383(9920):889-895.

Heslop P., Glover G. (2015) Mortality of people with intellectual disabilities in England: a comparison of data from existing sources. *Journal of Applied Research in Intellectual Disabilities*. 28(5):414-422.

Hodgson K., Deeny S.R., Steventon A. (2019) Ambulatory care-sensitive conditions: their potential uses and limitations. *BMJ Quality and Safety*. 28:429-433.

Hosking F.J., Carey I.M., Shah S.M., Harris T., DeWilde S., Beighton C., Cook D.G. (2016) Mortality among adults with intellectual disability in England: Comparisons with the general population. *American Journal of Public Health*. 106(8):1483-1490.

Hosking F.J., Carey I.M., Shah S.M., Harris T., DeWilde S., Beighton C., Cook D.G (2017) Preventable emergency hospital admissions among adults with intellectual disability in England. *Annals of Family Medicine*. 15(5):462-470.

Hourigan S., Fanagan S., Kelly C. (2018) *HRB statistics series 37: Annual report of the national intellectual disability database committee 2017*. Dublin: Health Research Board.

Howie V.A., Welch A.J., Horton E.S., Wirihana L.A. (2021) The quandary of registered nurses untrained in adult intellectual disability nursing when caring for this diverse patient group in acute care settings: An integrated literature review. *Journal of Clinical Nursing*. Early View, 00:1-14.

Hughes McCormack L.A., Rydzewska E., Henderson A., MacIntyre C., Rintoul J., Cooper S.A. (2017). Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population. *BJPsych Open.* 3(5):243-248.

Iacono T., Bigby C., Douglas J., Spong J. (2020) A prospective study of hospital episodes of adults with intellectual disability. *Journal of Intellectual Disability Research*. 64(5):357-367.

Jensen K.M. Davis M.M. (2013) Health care in adults with Down syndrome: A longitudinal cohort study. *Journal of Intellectual Disability Research*. 57:947-958.

Jukes M., Aspinall S.L. (2015) Leadership and learning disability nursing. *British Journal of Nursing*. 24(18):912-916.

Katterl R., Bywood P.T. (2011) *Primary health care for people with intellectual disabilities*. RESEARCH ROUNDup Issue 17. Adelaide: Primary Health Care Research and Information Service.

Kelly C.L., Thomson K., Wagner A.P., Waters J.P., Thompson A., Jones S., Holland A.J., Redley M. (2015) Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: a single-site study of 30-day readmission rates. *Journal of Intellectual Disability Research.* 59(9): 835-844.

Kelly C., Craig S., McConkey R. (2020) Supporting family carers of children and adults with intellectual disability. *Journal of Social Work*. 20(5):639-656.

Kessler S.K., Blank L.J., Glusman J., Thibault D., Massey S., Abend N.S., Szperka C.L., Crispo J.A., Willis, A.W. (2020) Unplanned readmissions of children with epilepsy in the United States. *Pediatric Neurology*. 108:93-98.

Krahn G.L., Fox M.H. (2014) Health disparities of adults with intellectual disabilities: what do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities*. 27(5):431-446.

Krahn G., Fox M.H., Campbell V.A., Ramon I., Jesien G. (2010) Developing a health surveillance system for people with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities*. 7(3):155-166.

Landes S.D., Turk M.A., Wong A.W. (2021) COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs. *Disability and Health Journal*, 14(2):101051.

Landes S.D., Turk M.A., Formica M.K., McDonald K.E., Stevens J.D. (2020) COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*. 13(4):100969.

Learning Disability Mortality Review. (2018). *The Learning Disabilities Mortality Review (LeDeR) Programme: Annual Report*. Bristol: University of Bristol.

Lindgren S., Lauer E., Momany E., Cope T., Royer J., Cogan L., McDermott S., Armour B.S., (2021) Disability, hospital care, and cost: utilization of emergency and in-patient care by a cohort of children with intellectual and developmental disabilities. *The Journal of Pediatrics*. 229:259-266.

Lunsky Y., Hastings R.P., Hensel J., Arenovich T., Dewa C.S. (2014) Perceptions of positive contributions and burnout in community developmental disability workers. *Intellectual and Developmental Disabilitie*s. 52(4):249-257.

McCarron M., Sheerin F., Roche L., Ryan A.M., Griffiths C., Keena P., Doody O., D'Eath M., Burke E., McCallion P. (2018) *Shaping the Future of Intellectual Disability Nursing in Ireland*. Dublin: Health Service Executive.

McCarron M., Cleary E., McCallion P. (2017) Health and health-care utilization of the older population of Ireland: comparing the intellectual disability population and the general population. *Research on Aging*. 39(6):693-718.

McDermott S., Royer J., Mann J.R., Armour B.S. (2018a) Factors associated with ambulatory care-sensitive Emergency Department visits for South Carolina Medicaid members with intellectual disability. *Journal of Intellectual Disability Research*. 62(3):165-178.

McDermott S., Royer J., Cope T., Lindgren S., Momany E., Lee J.C., McDuffie M.J., Lauer E., Kurtz S., Armour B.S. (2018b) Using Medicaid data to characterize persons with intellectual and developmental disabilities in five US states. *American Journal on Intellectual and Developmental Disabilities*. 123(4):371-381.

McDermott S., Hardin J.W., Royer J.A., Mann J.R., Tong X., Ozturk O.D., Ouyang L. (2015) Emergency Department and in-patient hospitalizations for young people with Fragile X Syndrome. *American Journal on Intellectual and Developmental Disabilities*. 120(3):230-243.

McDonnell A., Goodwin E., Kennedy F., Hawley K., Gerrish K., Smith C. (2015) An evaluation of the implementation of advanced nurse practitioner (ANP) roles in an acute hospital setting. *Journal of Advanced Nursing*. 71(4):789-799.

McMahon M., Hatton C. (2021) A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study. *Journal of Applied Research in Intellectual Disabilities*. 34(1): 316-325.

MENCAP. (2012) *Death by indifference: 74 deaths and counting, a progress report 5 years on*. London: MENCAP.

MENCAP. (2007) *Death by indifference*. London: MENCAP.

Metcalf E., Colgate R. (2019) Communication skills training for healthcare students working with people with intellectual disabilities. *BJPsych Advances*. 25(2):74-77.

Michael J. (2008) *Healthcare for all: report of the independent inquiry into access to healthcare for people with intellectual disabilities*. London: Department of Health.

National Federation of Voluntary Bodies. (1996) *A strategy for equality: Report of the commission on the status of people with disabilities*. Dublin: National Federation of Voluntary Bodies.

Nicholson E., Guerin S., Keogh F., Dodd P. (2019) Comparing traditional residential, personalised residential and personalised non-residential respite services: Quality of life findings from an Irish population with mild–moderate intellectual disabilities. *British Journal of Learning Disabilities*. 47(1):12-18.

Noble H., Smith J. (2018) Reviewing the literature: choosing a review design. *Evidence Based Nursing*. 21(2):39-41.

O'Hara J., McCarthy J., Bouras N. (2010) *Intellectual disability and ill health: A Review of the Evidence*. Cambridge University Press, Cambridge.

O'Leary L., Cooper S.A., Hughes McCormack L. (2018) Early death and causes of death of people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*. 31(3):325-342.

Purdy S., Griffin T., Salisbury C., Sharp D. (2009) Ambulatory care-sensitive conditions: terminology and disease coding need to be more specific to aid policy-makers and clinicians. *Public Health*. 123(2):169-173.

Reppermund S., Srasuebkul P., Heintze T., Reeve R., Dean, K., Emerson, E., Coyne D., Snoyman P., Baldry E., Dowse L., Szanto, T. (2017) Cohort profile: a data linkage cohort to examine health service profiles of people with intellectual disability in New South Wales, Australia. *BMJ Open*. 7(4):p.e015627.

Robertson J., Hatton C., Baines S., Emerson E. (2015) Systematic reviews of the health or health care of people with intellectual disabilities: a systematic review to identify gaps in the evidence base. *Journal of Applied Research in Intellectual Disabilities*. 28(6):455-523.

Sandberg M., Ahlström G., Kristensson J. (2017) Patterns of somatic diagnoses in older people with intellectual disability: a Swedish eleven-year case control study of in-patient data. *Journal of Applied Research in Intellectual Disabilities*. 30(1):157-171.

Schalock R.L., Luckasson R., Tassé M.J. (2021) *Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports*. 12th Edition. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schuengel C., Tummers J., Embregts P.J.C.M., Leusink G.L. (2020) Impact of the initial response to COVID-19 on long-term care for people with intellectual disability: an interrupted time series analysis of incident reports. *Journal of Intellectual Disability Research*. 64(11):817-824.

Sowney M., Barr O. (2007) The challenges for nurses communicating with and gaining valid consent from adults with intellectual disabilities within the accident and emergency care service. *Journal of Clinical Nursing*. 16(9):1678-1686.

Taggart L., Cousins W. (2014) *Health promotion for people with intellectual and developmental disabilities*. Berkshire, UK: McGraw-Hill Education.

Tomlinson M., Yasamy M.T., Emerson E., Officer A., Richler D., Saxena S. (2014) Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *Journal of Intellectual Disability Research*. 58(12):1121-1130.

Turk M.A., Landes S.D., Formica M.K., Goss K.D. (2020) Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*. 13(3):100942.

Venkat A., Pastin R.B., Hegde G.G., Shea J.M., Cook J.T., Culig C. (2011) An analysis of ED utilization by adults with intellectual disability. *American Journal of Emergency Medicine*. 29(4):401-411.

Wadhera R.K., Joynt Maddox K.E., Kazi D.S., Shen C., Yeh R.W. (2019) Hospital revisits within 30 days after discharge for medical conditions targeted by the hospital readmissions reduction program in the United States: National retrospective analysis. *BMJ*. 366:l4563.

Ward R.L., Nichols A.D., Freedman R.I. (2010) Uncovering health care inequalities among adults with intellectual and developmental disabilities. *Health and Social Work*. 35(4):280-290.

Williamson T., Flowers J., Cooke M. (2012) Quantifying Emergency Department admission rates for people with a learning disability. *Emergency Medicine Journal*. 29(9):771-772.

Wright, P. (2018) 'Patient and Family-Centred Care –An Introduction with Paul Wright' Available at https://youtu.be/gvGJs6liD5I Accessed on 14 May 2021.

World Health Organization. (2011) *World report on disability*. Geneva: World Health Organization.

Appendix 1 Ethical approval

UNIVERSITY OF LIMERICK
OLLSCOIL LUIMNIGH

Ollscoil Luimnigh
University of Limerick

4th February, 2021

Dear Owen

Thank you for providing the documentation relating to your NQAIS Clinical National Data access approval.

Study Title:	**National Quality Assurance & Improvement System (NQAIS) Clinical National level data access**
EHS REC Reference No	**2021_02_21_EHS (OA)**
UL Named Researchers	**Dr Owen Doody**

The Education and Health Sciences Research Ethics Committee (EHSREC), University of Limerick is happy to accept this approval and note you have been granted viewer access to the NQAIS Clinical National Data. Please note we have allocated your study the following reference number: 2021_02_21_EHS (OA).

I would like to take this opportunity to wish you well with your study.

Ronni M. Greenwood, PhD
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Appendix 2 Coding Framework

Coding Framework

1. Drawn down from NQAIS of 164 Hospitals
2. List of intellectual and developmental disabilities sourced from Local HIPE coder
3. Verified and grouped into two groups, namely, A *Intellectual Disability* and C *Developmental Disability* (unsure of an ID presence)
4. NQAIS Codes applied to each condition and groups
5. Columns K and L filtered for Codes
6. Retrieved data presented in three MS Excel sheets, then merged

Group A) ID Conditions

	Code	***Condition***
1.A	B069	Rubella
2.A	B589	Toxoplasmosis
3.A	D821	DiGeorge syndrome (22q11.2del) *
4.A	E752	Canavan’s Disease
5.A	E754	Batten Disease
6.A	E750	Tay-Sachs Syndrome
7.A	E761	Hunters Syndrome
8.A	E760	Hurlers Syndrome
9.A	E791	Lesch Nyhan Syndrome
10.A	F842	Rett Syndrome
11.A	G404	West Syndrome
12.A	Q000	Anencephaly
13.A	Q02	Microcephaly
14.A	Q0434	Lissencephaly
15.A	Q851	Tuberous Sclerosis
16.A	Q8702	Apert Syndrome
17.A	Q8711	Cockayne Syndrome
18.A	Q8712	Cornelia de Lange Syndrome
19.A	Q8724	Rubenstein-Taybi Syndrome
20.A	Q8732	Sotos Syndrome
21.A	Q8782	Lawrence-Moon-Biedl Syndrome
22.A	Q8785	Angelman Syndrome

23.A	Q8713	Niemann-Pick Disease
24.A	Q8714	Prader-Willi Syndrome
25.A	Q8717	Smith-Lemli-Opitz Syndrome
26.A	Q8784	Williams Syndrome
27.A	Q909	Down Syndrome
28.A	Q913	Edwards Syndrome
29.A	Q917	Patau's Syndrome
30.A	Q92	
31.A	Q933	Wolf-Hirschhorn Syndrome
32.A	Q934	*Cri-du-chat* Syndrome
33.A	Q94	
34.A	Q95	
35.A	Q96	Turner Syndrome
36.A	Q970	Triple X Syndrome
37.A	Q971	Pentasomy-49, XXXXX*
38.A	Q984	Klinefelter Syndrome
39.A	Q981	49, XXXXY syndrome* Klinefelter syndrome, male with more than two X chromosomes
40.A	Q985	XYY syndrome* Karyotype 47,XYY
41.A	Q992	Fragile X Syndrome
42.A	Q998	Tetrasomy-XXXX*

Group C) Developmental Disability (unsure of an ID presence)

	Code	**Condition**
1.C	E030	Congenital Hypothyroidism with diffuse goitre
2.C	E031	Congenital Hypothyroidism without diffuse goitre
3.C	E701	Phenylketonuria
4.C	E720	Lowe Syndrome
5.C	E721	Homocystinuria
6.C	E742	Galactosaemia
7.C	E750	Sandhoff Syndrome
8.C	E752	Neurofibromatosis
9.C	E763	Mucopolysaccharidoses
10.C	F845	Asperger’s Syndrome
11.C	F840	Autism Spectrum Disorder
12.C	F90.0	Attention Deficit Hyperactive Disorder
13.C	G80	Cerebral Palsy
14.C	R628	Failure to thrive
15.C	Q059	Spinabifida
16.C	Q751	Crouzon Syndrome
17.C	Q850	Neurodevelopmental*
18.C	Q860	Foetal Alcohol Syndrome
19.C	Q8787	Velocardiofacial

HSE

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