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**Health Literacy Levels in Women at Risk of  
Gestational Diabetes Mellitus attending antenatal  
services in University Hospital Galway**

**Single Volume**

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In fulfilment of the requirements for the MD Degree

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**Discipline of Medicine**

National University of Ireland, Galway

10th May, 2017

## Introduction

## Introduction

*"Health literacy can be described as both a goal and an outcome, becoming the currency and capital needed to develop and sustain health"*

Nutbeam D, 2000

## Introduction

### **Presentations arising from this research**

Finn Y, Carmody L, Dunne F Prevalence of Limited Health Literacy in Women at Risk of Gestational Diabetes 9<sup>th</sup> West of Ireland Integrated Diabetes Care Conference October 2016

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## Summary of Contents

### **Introduction**

The 2011 population study on health literacy found that 40% of the Irish population had inadequate health literacy. There has been little research in Ireland and internationally on health literacy in pregnancy. This research explores health literacy levels in women at risk of gestational diabetes (GDM).

### **Methods**

Pregnant women at risk of GDM were interviewed on the day of their oral glucose tolerance test (OGTT) at University Hospital Galway. Both functional health literacy and general health literacy, using the Newest Vital Sign (NVS) (U.K.) and the Health Literacy Survey Questionnaire respectively, were measured. Socio-demographic parameters and clinical data were captured from a participant questionnaire and from data sourced from hospital electronic databases. Pregnancy outcomes were collected from the hospital maternity database and results of the OGTT were sourced from the hospital laboratory database.

### **Results**

There were 297 participants, of which 30 (10.3%) were diagnosed with GDM. Limited functional health literacy was found in 75 participants (25.3%) and limited general health literacy in 113 participants (38%). Household income, parental ethnic background, education attainment and social status were predictors of limited health literacy ( $p<0.05$ ). A higher percentage of mothers with adequate functional health literacy took pre-pregnancy folic acid compared with mothers with limited functional health literacy, 67.8% versus 53.5% ( $p=0.04$ ). Results indicated that 16.7% (12 of 75) of pregnant women with limited functional health literacy were diagnosed with GDM compared with 6.2% (18 of 222) of pregnant women

## **Introduction**

with adequate functional health literacy. This did not reach statistical significance ( $p = 0.6$ ). Following adjustment for confounders functional health literacy was no longer significantly associated with pre-pregnancy folic acid. There were no significant associations found between general health literacy and pregnancy-related factors or adverse pregnancy outcomes.

## **Conclusions**

This study confirms that limited health literacy is present in a significant proportion of pregnant women at risk of GDM. It also indicates a social gradient in health literacy in this population. Further studies are required to better define the relationship of health literacy in this cohort and the role of confounders. This study provides prevalence data that can be used to inform the design of these studies. Inclusion of screening questions or short subjective measures of health literacy may identify an accurate and practical test to screen for limited health literacy in this population.

**Declaration**

I declare that this thesis is all of my own work, from its inception to its completion. I declare that I have not obtained a degree in this University or elsewhere on the basis of this work.

### **Acknowledgements**

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## **Abbreviations**

ALLS Australian Adult literacy and Life skills Survey

BMI Body Mass Index

DP-HL Disease Prevention Health literacy

EU-HLS European Health Literacy Survey

EU-HLS-Q European Health Literacy Survey Questionnaire

GDM Gestational Diabetes

GEN-HL General Health Literacy

HAPO Hyperglycaemia and Adverse Pregnancy Outcomes

HALS Health Activity Literacy Scale

HbA1c Glycosylated hemoglobin

HC-HL Health Care Health Literacy

HL Health Literacy

HP-HL Health Promotion Health Literacy

HSE Health Service Executive

IADPSG international Association of Diabetes and Pregnancy Study Groups

IALS International Adult Literacy Survey

NAAL National Assessment of Adult Literacy

NALA National Adult Literacy Agency

NALS National Adult Literacy Survey

NVS (U.K.) Newest Vital Sign (U.K.)

REALM Rapid Estimate of Adult Literacy in Medicine

REALM-R Rapid Estimate of Adult Literacy in Medicine Revised

S-TOFHLA Short Test of Functional Health Literacy in Adults

TOFHLA Test of Functional Health Literacy in Adults

WHO World Health Organisation

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## **Section 1. Introduction**

### **1.1 Literature review: search strategy**

The aim of the literature review was to identify, summarise and appraise current knowledge and understanding in the research subject areas. It also served to refine the research questions by confirming a gap in the literature, and demonstrate that my research findings will add something new to the current literature on health literacy. Whilst not performing a systematic review, I adopted components of the methodology by using the following databases in my search: Medline (OVID), CINAHL PLUS (EBSCO) and SCOPUS (Elsevier). I also employed Google Scholar search engine, to identify publications in the grey literature, to source additional articles and reports on the history of literacy and health literacy and data from population studies. Articles and reports were identified using the following search terms: health literacy, literacy, health literacy measures, maternal health literacy, gestational diabetes, pregnancy outcomes and health outcomes. Articles sourced from healthcare databases were review articles, original studies and comments (letters and editorials). Publications sourced from Google scholar were reports, book chapters and theses. The literature search on Medline, CINAHL and SCOPUS was from the period of 1990 to 2016. Search using Google scholar was not limited by date. The review process was traditional and not systematic; the process involved skimming of publication titles, followed by reading of relevant abstracts and full articles. It was cross-disciplined covering medicine, nursing, public health and epidemiology.

## **1.2 History and Definitions of Health Literacy**

The term health literacy was first used in 1974 by Simonds in a paper on health education as a policy issue affecting the health care system (1). At the time there was evidence that increasing health care budgets alone did not result in better health outcomes (1). Health education, linked closely to schooling and education was becoming recognised as a determinant of health. In today's healthcare systems, which are constantly being updated and restructured, with more sophisticated and complex treatment options, and with the evolving role of the individual as an active participant in his/her own health, health literacy problems are growing (1).

### *History of Health Literacy*

Health literacy was preceded and influenced by work on literacy which evolved from the 1800s. Initially authorities were concerned with determining what constituted a literate or illiterate person. In the 1880s in the U.S. authorities crudely determined a person's literacy status by the ability to sign his or her own name, as opposed to putting an X where a signature was required on a legal document (2). This was followed by using methods, such as self-reported ability to read and write, and recording of years of formal schooling. In tandem with the economic development from a predominantly agricultural-based economy to an industrial and information-based economy, the authorities were concerned with measuring functional literacy, which was thought to be linked to a person's ability to fulfil his or her role in employment and in society, in general.

While levels of illiteracy in the U.S. dropped dramatically, from about 20% in the 1870s to less than 0.6% a century later, there was an increasing level of sophistication in the workplace and society, and, in response to this, the authorities (Department of Education, National Academy of Education) gradually increased the number of years in fulltime education which met

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the definition of literacy. It became apparent, while levels of illiteracy were decreasing, there was an increasing number of people with low literacy levels, which was becoming a national concern (2). Measures and definitions of low literacy were varied, making it difficult to define the scale of the problem. This was addressed by the National Literacy Act, which defined literacy in 1991 as “an individual’s ability to read, write and speak in English, and compute and solve problems at a level of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential” (3). This definition, includes not only functional literacy (ability to read and write) but implies cognitive skills, such as understanding and creating new knowledge. In the population literacy surveys which followed, items on health literacy, presented as health-related tasks, were included. The results of the 1993 National Adult Literacy Survey (NALS), which assessed prose literacy, document literacy and quantitative literacy skills, indicated that 21–23% of the adult population was in the lowest of 5 literacy levels and another 25–28% was in Level 2; the conclusion that 90 million Americans lacked adequate literacy skills received widespread media attention (3). A follow up national assessment of adult literacy in 2003 included a component on health literacy, defined as the ability to use literacy skills in understanding health-related materials and forms (4). Thirty six percent had either basic or below basic health literacy skills. Scholarly activities, which focused on defining health literacy, development of validated health literacy tools and increasing awareness of the link between low health literacy and health outcomes have advanced the field of health literacy in the U.S. Health outcomes that are associated with low literacy include patient use of emergency services, disease prevention measures, adherence to medication instruction and mortality. Research studies have shown that these associations persist after adjustments for confounders such as education attainment, income level, employment status, socio-economic status and ethnic background (5). This theme will be explored in more detail later in this section (1.4) and in the discussion (section 4).

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Similarly in Canada literacy levels were originally gauged by recording the number of signatures versus marks on documents, such as, church baptismal and marriage certificates (6). Authorities worked on methods to develop more accurate ways of capturing literacy and started to define literacy according to years of schooling completed. By the 1970s the Canadian Association for Adult Education (CAAE) stated that one had to have completed the 8<sup>th</sup> grade in order to be ‘functionally literate’ (7). In Canada the 8<sup>th</sup> grade is part of the middle school (in most Canadian states grades 6<sup>th</sup> to 8<sup>th</sup> form the middle school) and pupils are aged between 12 and 14 years (8). This is equivalent to year 10 of the U.K. educational system, which is the first year of the General Certificate of Secondary Education (GCSE), a 2 year programme (9). In Ireland the Canadian 8<sup>th</sup> Grade is equivalent to the second year of secondary school, part of the junior cycle. Canada conducted a number of national literacy surveys and participated in international literacy surveys, including the International Adult Literacy survey (IALS) in the 1980s and 1990s. Results from the IALS reports that 42% of adults between 16 and 64 years scored at the lowest 2 levels of literacy (10). Following the IALS report the Canadian Public Health Association has conducted a number of health literacy surveys and published reports on national health literacy strategies, including “A vision for a health literacy Canada” (11).

Data and strategies on literacy in Ireland, evolved in the 1990s, where its development stemmed from the findings of adult literacy surveys, health promotion policies and development of a national health literacy strategy by the National Adult Literacy Agency (NALA) (12). The first population survey on literacy in Ireland was published in 1997 and presented data from the 1995 International Adult Literacy Survey (IALS) (13). Almost 2,500 Irish adults between 16 and 64 years participated, with a response rate of 60%. The survey measured prose literacy, document literacy and quantitative literacy and used a 5 point scale from 1 to 5. Level 3 represented the minimum level “needed to actively engage in Irish

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society". Items involved tasks that one would be required to carry out in everyday life, with some related to health e.g. instructions on taking aspirin. In comparison to a number of countries in Europe, Canada and the U.S. Ireland performed poorly, with 25% being below level 1 (very low literacy skills) and 30% below level 2 (people that can only engage with literacy tasks that are simply presented and not complex) (12). Twenty three percent of Irish adults had difficulty reading directions of use on a popular headache package. The report concluded that 53% of the Irish sample were not 'functionally literate'. Participants who scored at the lowest level, level 1, were more likely to be unemployed, be in the lower income group and have left school before completion of the junior cycle in secondary school, than those in the highest levels (levels 4/5). The Survey of Lifestyle, Attitudes and Nutrition (SLÁN), conducted in 1998, recruited adult participants 18 years and older, and data was collected using a self-completed questionnaire (14). The sample was stratified across the 26 counties and the sample size was 6,539, with a response rate of 62.2%. The results of SLÁN revealed that 17.4% of participants were unable to read or understand information, preventing them from improving their general health. When asked 6.4% of respondents also reported that "they think their health would be better if they had it easier to read health information". These surveys attracted the attention of policy makers and lead to inclusion of adult literacy measures in the National Development Plan (NDP) 2000 – 2006, and the first National Adult Literacy Strategy published by the Department of Education and Science in 2000 (15). At the same time a National Health Promotion strategy was published by the Department of Health and Children and this stated that literacy was one of the factors contributing to health inequalities (16). In 2003 NALA launched a 'Plain English service', followed by the publication of a position paper on Health Literacy in 2007, where its mission is stated "to make the Irish health service literacy friendly where both the skills of individuals and the literacy demands of the health service are analysed. It wants to see a health service where literacy is not a barrier. It will work to influence the

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health service in every context: promotion, protection, prevention, access to care and maintenance” (17). More recent developments in this area are the development of a Literacy Audit Tool in Healthcare by NALA and the joint NALA/MSD health literacy awards (18). A health literacy programme has been developed by a joint collaboration between the Irish Pharmacy Union, NALA and the Pharmaceutical company Merck Sharp and Dohme (MSD), called the Crystal Clear Pharmacy programme which awards pharmacies who “deliver a health literacy friendly service to their patients”(19). More recently the ICGP has joined the Crystal Clear Programme, promoting health literacy in general practice, with the launch of a Crystal Clear General Practice Programme (20).

Data on health literacy levels in Ireland are now available from the recent (2011) European Health Literacy Survey, results from Ireland report (21). This survey and its results from Ireland will be discussed in detail in chapters 2 and 3, Measurement of Health Literacy and Population based Surveys on Health Literacy respectively.

As a member of the European Union, Ireland is governed by the European Commission’s policies on health, which promote cooperation among the member states on issues that affect all members. The health strategy outlined in the 2007 publication of the European Commission “European Commission: Together for health: a strategic approach for the EU 2008-2013” includes the promotion of health literacy programmes as a major action point (22).

### *Health Literacy Concepts and Definitions*

Weiss describes health literacy as “the ability to use and interpret text, documents, and numbers effectively, skills that might seem to be distinct but are highly correlated with one another” (23). Definitions of health literacy have been proposed and refined since the term was first

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introduced in the 1970s. Definitions listed in table 1.1 use similar “action words” to describe the skills the individual requires to promote and maintain good health, such as, ability “to access”, “to use”, “to understand” and “to process information”. Other action words used are the following:

*to perform, to seek out, to find, to communicate, to act, to take responsibility, to interpret, to filter, to derive meaning, to evaluate, to appraise, to identify*

It is clear that there is a range of skills needed to maintain health and relying solely on task-based actions, such as “to read, to write and to calculate” would not be sufficient to function in the healthcare environment in promoting and maintaining one’s health (24, 25). Adams et al. give examples of terms that a person with low health literacy (but who has adequate reading skills) may have difficulty understanding, such as “Colon”, “Polyp” and “Prognosis” (25). Limiting the definition of health literacy to the tasks of “read, write and calculate” and/or to skills required in the healthcare setting are viewed as narrow definitions. Literacy in the healthcare setting is sometimes referred to as medical health literacy, clinical health literacy, or patient health literacy (26). The term functional health literacy is a similar term and corresponds to level 1 in the health literacy dimensions described by Nutbeam and which are explained further on in this section (27). The skills and competencies which are frequently included in more recent and broader definitions of health literacy include cognitive skills, communication skills, personal skills and motivation.

A number of definitions, especially the earlier ones, focus on the individual and the skills required to maintain health. Examples are the definitions by the American Medical Association (AMA), the Institute of Health (IOH), the World Health Organisation (WHO) 1998 definition and Nutbeam’s definition; these definitions enumerate skills required to access and understand health information and health services to maintain health

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(table 1.1) (27-30). Some definitions specify the context or settings of health literacy; such as the healthcare system (e.g. AMA definition) or health services and health information (which could include material in printed or digital format or in the media (Institute of Medicine definition). Rootman and Gordon-El-Bihbety expand the context further stating that health literacy is “the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course”; this avoids limiting the role of health literacy to maintaining health in healthcare settings, a view endorsed by Kickbusch and Maag who clarify that “almost every aspect of our lives is faced with questions and decisions about health, as the sphere of health has expanded far beyond the confines of the health-care system itself” (31). In this age of an information-based economy and society or as Kickbusch and Maag describe it “in modern health societies”, people are “confronted by a variety of health information from the news media, the internet, TV and radio, family and friends, popular

### Definitions of health literacy

American Medical Association (1999)	“The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment”(28)
Institute of Medicine (2004)	“The individuals capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (29)
WHO (1998)	“The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (30)
Nutbeam (2000)	“The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health” (27)
Berkman et al. (2010)	“The degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions” (2)
Zarcadoolas et al. (2005)	(Dynamic definition) “The wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and

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	concepts to make informed choices, reduce health risks and increase quality of life (32)
Kickbusch & Maag (2008)	The ability to make sound health decisions in the context of everyday life-at home, in the community, at the workplace, the health care system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, the ability to seek out information and their ability to take responsibility (31)
Rootman & Gordon-El-Bihbety (2008)	The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course (11)
Freedman et al. (2009)	Public health literacy is the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community (33)
Baker (2006)	The ability to function in the health care environment and depends on characteristics of both the individual and the health care system. An individual's health literacy is context specific (dynamic) and may vary depending upon the medical problem being treated, the health care provider, and the system providing care. The definition includes health knowledge (34)
Australian Bureau of Statistics (2008)	The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy (35)
Macuso (2008)	A process that evolves over one's lifetime and encompasses the attributes of capacity, comprehension and communication (43)
Adams et al. (2009)	The ability to understand and interpret the meaning of health information in written, spoke or digital form and how this motivates people to embrace or disregard actions relating to health (25)
Sorensen K et al. (2012)	Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (36)
WHO (2015)	Health literacy can be defined as the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health

Table 1.1: Definitions of Health Literacy

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media, governmental health organizations, healthcare providers, health associations, books, peer-reviewed journals, and health insurance organizations" (31). Based on the many sources of information on health and health-related topics available in modern societies, it is not surprising that some definitions include the ability to access, understand and interpret information from sources such as the media, social contacts, printed and digital communications. Explicit reference to types of health information i.e. "written, spoken and digital" is made in the definition by Adams et al. (table 1.1) (25). A number of definitions reference skills/action words to "health information" (and not healthcare systems), which in our modern information-driven society has many and varied sources. We are constantly confronted with health information, regardless of the setting, information which can be used to help us to stay healthy, outside of the healthcare services. For example we can choose to act on health information concerned with nutrition and lifestyle to promote health; similarly health information can be used in disease prevention and to avoid accidents. Making appropriate health decisions in dimensions, such as health promotion and disease prevention, may not require seeking information or services from the health service providers but from other organisations such as citizen centres, social and community organisations. Online and printed information are other sources of information for individuals.

These dimensions of health literacy are referred to by the Australian Bureau of Statistics who define health literacy as "the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment..." and Rootman and Gordon-El-Bihbety who state health literacy is "the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health..."(11, 35). Sorensen et al. proposed an 'all inclusive' definition following a systematic review of definitions and

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concepts of health literacy in the literature (36). They define health literacy as making judgments and decisions “concerning healthcare, disease prevention and health promotion” (table 1.1). The role of health literacy, outside of healthcare settings, and as a determinant of health promotion and disease prevention (in addition to treatment) are complementary and are now viewed in our broader understanding and definitions of health literacy and reflected in many of the definitions in table 1.1.

There has been some discussion in the literature on whether health literacy is a static or dynamic state. Kickbusch et al. propose a definition which is “active, dynamic and empowering” and is a life skill required to navigate modern society (37). Zarcadoolas et al. include this concept of a dynamic process in their definition: “The wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life” (table 1.1) (32).

Macuso defines health literacy as a “process that evolves over one’s lifetime and encompasses the attributes of capacity, comprehension and communication” (38). Health literacy contexts vary over one’s lifetime and health issues confronting teenagers, parents and the elderly differ widely. For example parents are responsible for their children’s health which involves understanding immunisations on offer (and making decisions on these on behalf of their children), developmental checks and making decisions when they are ill as to the appropriate responses to get them better. Adult children frequently need to take responsibility of their elderly parents’ health which can involve engaging with multiple health care services, requiring adequate navigation skills, and making decisions based on health, social, economic and personal preferences, to maintain both physical and psychological health of their parents. Kickbusch and Maag comment that “Health literacy is also dynamic, as health-literate individuals are involved in continuous exchange and dialogue with the environments they are living in” (31). While other definitions do not

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explicitly mention a dynamic process there is reference to understanding and interpreting health information, which acts as a changing platform, on which an individual's skills and competencies in health literacy develop.

Nutbeam describes health literacy, in an outcome model for health promotion, as an intermediate health promotion outcome (27). In this outcome model of health promotion, health and social outcomes e.g. mortality and morbidity outcomes, and quality of life, are the end stage outcomes of interventions, with determinants of health and social outcomes, and health promotion outcomes, which includes health literacy, forming intermediate intervention outcomes. Health literacy is a target for interventions aimed at improving knowledge and understanding of the determinants of health, changes in attitudes and self-efficacy (27). Within this framework Nutbeam describes 3 dimensions of health literacy: basic or functional health literacy, communicative or interactive health literacy and critical health literacy (27). These dimensions of health literacy are derived from similar dimensions in the literacy fields: basic literacy, interactive literacy and critical literacy. Level 1, functional health literacy, as an outcome is the "communication of factual information on health risks, and on how to use the health system". Outcomes can be measured in terms of knowledge of health risk, knowledge of the health service and compliance with prescribed medication. Level 2, interactive health literacy, has a focus on the "development of personal skills in a supportive environment" (27). Skills developed include an individual's ability to act independently and with confidence, with improved motivation. Level 3, critical health literacy, reflects the "cognitive and skills development outcomes which are orientated towards supporting effective social and political action, as well as individual action". Critical health literacy can lead to engagement in community action groups, advocacy and advisory roles in economic, political and social issues affecting determinants of health. Benefits are both to the individual and the community. These 3 dimensions can be viewed as a set of competencies and skills of increasing sophistication and

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complexity leading to enhanced empowerment of individuals and benefits to both the individual and the community (figure 1.1).

Kickbursh and Maag state that being “health literate means placing one’s own health and that of one’s family and community into context, for example, by understanding one’s current health state as well as the socioeconomic factors and cultural values that influence it”(31). The authors describe health literacy as a life skill and as “an essential part of social capital”. Social capital is a term used for “the resources embedded in social relations among persons and organizations that facilitate cooperation and collaboration in communities” (39). This broader concept or health literacy extends beyond the individual and involves family, social contacts and the community; this is supported by definitions that stem from public health and health promotion, and are explicit in Nutbeam’s, Kickbusch & Maag’s and Freedmann’s definitions (table 1.1). This broad view of health literacy has been endorsed by the WHO in its updated definitions on health literacy 2015 (table 1.1). Sorensen et al. conducted a systematic review on concepts and definitions of health literacy in 2009/2010 and combined the essential components of definitions to create a comprehensive definition (table 1.1) (36). This definition names core competencies, skills, domains and outcomes of health literacy identified in the review.

### *Health literacy and empowerment*

Health policy makers refer to empowerment of individuals and communities in their policies (22). The WHO 7<sup>th</sup> Global conference on health promotion, defines health literacy in this context and states “By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment” (40). Kickbusch and Maag endorse this concept of health literacy as a moderator of empowerment, enabling the individual and the community to take

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responsibility for and to make decisions on health matters (31). Sorensen et al. regard health literacy as “an asset for improving people’s empowerment within the domains of healthcare, disease prevention and health promotion” (36). Health literacy as an outcome can be measured as improved knowledge and understanding of health determinants (social, environmental, cultural, political), changes in attitudes and motivations, all of which lead to empowerment (27).

Health literacy is a prerequisite for individuals to participate effectively in health care services, which are becoming more and more complex, with increasing numbers and type of service providers. This involves navigation of the healthcare services and forming a partnership with health care professionals, which forms the basis of modern healthcare provision in developed countries (31). With increasing health literacy competencies and skills, as depicted by Nutbeam’s levels of health literacy, individuals and communities can achieve greater empowerment and health benefits (figure 1.1).

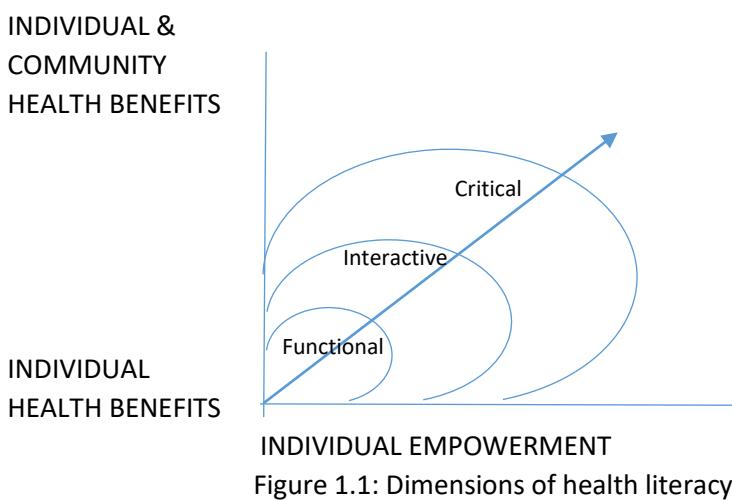


Figure 1.1: Dimensions of health literacy

### **1.3 Measurement of Health Literacy**

A number of measures of health literacy have been developed which can be used as screening tools in clinical environments (table 1.2). These include the Test of Functional Health Literacy in Adults (TOFHLA), Rapid Estimate of Adult Literacy in Medicine (REALM) and the Newest Vital Sign (NVS) (23, 41, 42). These tools measure functional health literacy and are concerned with the skills, such as reading, writing and numeracy skills, which are required to read and act on prescriptions, appointment cards, medicine labels and instructions for home health care.

The TOFHLA tool provides participants with medical information used in clinical practice, such as instructions on preparation for procedures, prescription instructions, pill boxes and appointment slips; participants answer questions which test reading and comprehension, and numeracy literacy (41). The test takes 22-25 minutes to administer and is used mostly in health literacy research settings. The TOFHLA was shortened by reducing the original 3 prose passages to 2 and from 17 numeracy items to 4 in the short TOFHLA (S-TOFHLA), which takes 8-12 minutes to administer (43). The authors, Baker et al., reported Cronbach's  $\alpha$  of 0.68 for the numeracy items and 0.97 for the prose items (43). Correlation with the REALM was high with a correlation co-efficient of 0.80. The main disadvantage is the relative long administration time of TOFHLA and S-TOFHLA which makes them unsuitable to administer in busy clinical settings and therefore, these health literacy tools are used mostly in health care research.

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MEASURE	DOMAINS of HEALTH LITERACY MEASURED	NUMBER of ITEMS	TIME to COMPLETE in MINUTES	Used in health literacy surveys	Correlation with health literacy measure(s)	Reliability
TOFHLA (Test Of Functional Health Literacy in Adults)	Functional health literacy	50 reading & 17 numeracy items	22	Yes (multiple)	REALM r =0.84	Cronbach's $\alpha$ = 0.96
S-TOFHLA	Functional health literacy	36 reading & 4 numeracy items	7	Yes (multiple)	TOFHLA r= 0.91 REALM r = 0.80	Cronbach's $\alpha$ = 0.97
REALM (Rapid Estimate of Adult Literacy in Medicine)	Functional health literacy	66 reading items	5-6	Yes (multiple)	TOFHLA r = 0.84	Test-retest reliability coefficient= 0.98
REALM-R	Functional health literacy	8 reading items	<2	Yes (multiple)	REALM r = 0.72 METER r = 0.73	Cronbach's $\alpha$ = 0.91
NVS (Newest Vital Sign) U.K.	Functional health literacy	2 reading & 4 numeracy items	<3	Yes (multiple)	TOFHLA r = 0.49	Cronbach $\alpha$ = 0.74
SLS (Short Literacy Screening)	Functional health literacy	2 reading & 1 comprehension items	Not stated likely < 5	Yes (multiple)	S-TOFHLA r = 0.33 REALM r = 0.26	Cronbach $\alpha$ = 0.74
METER (Medical Term Recognition Test)	Functional health literacy	80 reading items	2	Yes (multiple)	REALM r = 0.74	Cronbach's $\alpha$ = 0.93
HALS (Health Activity Literacy Scale)	Health Promotion health Protection Disease Prevention Health Care & Maintenance Systems Navigation Total	60 items 65 items 18 items 16 items  32 items 191 items	Approx. 60	No (U.S. population surveys only)	not stated	Cronbach's $\alpha$ = 0.93
HLS (Health Literacy Survey)	Health care Disease prevention Health promotion Total	16 items 16 items 15 items 47 items	<22	Yes (Europe and Asia)	NVS r = 0.25	Cronbach's $\alpha$ GEN HL = 0.97 HC HL = 0.91 DP HL = 0.91 HP HL = 0.92

Table 1.2 Measures of Health Literacy

The REALM is a 66 item health-related word recognition test, takes 2-3 minutes to administer and tests reading and word pronunciation. It was developed in the U.S. to help physicians identify adults with limited reading skills in primary care. Items (medical terms) are presented in a list of

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increasing difficulty and participants are asked to read them out loud (42). This test does not test comprehension or numeracy skills. In addition the administration time has been found to be 5-6 minutes in busy clinical settings. It demonstrates good correlation with the TOFHLA, with a Spearman's rho of 0.84 and has a test-retest reliability of 0.98; Cronbach's  $\alpha$  is not reported by the authors (42). In response to the long administration time Bass et al. developed a shortened test of the REALM, the REALM-R, which consists of 8 items and takes less than 2 minutes to explain and administer (44). The authors reported good internal consistency with a Cronbach's  $\alpha$  of 0.91 and a part whole correlation between the REALM-R and the REALM of 0.72, confirming high reliability and moderately high validity.

The SILS consists of 3 items and tests confidence in filling out a form, reading and comprehension (1 item each) and has been validated against the S-TOFHLA and the REALM (45). The items are "How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?", "How often do you have problems learning about your medical condition because of difficulty understanding written information?" and "How confident are you filling out forms by yourself?" Responses are scored on a Likert scale from 0 to 4. Internal consistency was moderately high with a Cronbach's alpha of 0.74. Correlations with the S-TOFHLA and the REALM were low with a Spearman's rank coefficient of  $r= 0.33$  and  $r=0.26$  respectively.

Rawson et al. developed the METER test which consists of 80 reading terms; 40 medical terms and 40 non words (46). Patients are asked to mark items they recognise as actual words and the test takes 2 minutes to administer. The advantage of the METER over other measures of functional health literacy is that it is self-administered, as the participant is given the list of words and is asked to tick those words he/she recognises as actual words, and, secondly, there is a lower risk of causing discomfort or embarrassment to the participant compared with other measures. The

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authors reported that the METER had good internal consistency with a Cronbach's alpha of 0.93 and was strongly correlated with the REALM with a correlation coefficient of 0.72. This is not surprising as there was considerable overlap of medical terms used in the REALM and the METER.

The NVS was developed by Weiss et al in 2005: this is a fictitious ice cream nutritional label accompanied by 6 questions testing reading, comprehension and numeracy literacy (20). It takes up to 3 minutes to administer. Each item has a score of 1 with a total score of 6. The numeracy items test comprehension, ability to locate the required information for test items, in addition to calculation skills, while the comprehension items demand abstract reasoning skills in addition to comprehension. For example the patient is asked to imagine he/she has an allergy to peanuts. This measure is indexed in appendix E. A score of 0 or 1 indicates high likelihood of limited health literacy, a score of 2 or 3 possible limited literacy and scores between 4 and 6, adequate literacy. Rowlands et al. amended the NVS to reflect U.K. nutrition labelling and validated the new version NVQ-UK against the TOFHLA (47). Pearson's correlation coefficient was 0.49 and internal consistency was moderately high with a Cronbach's alpha of 0.74 (table 1.2).

Kiechle et al. compared the above 6 brief measures of functional health literacy in a busy clinical setting, where they administered the 6 tests to 400 patients attending an emergency department in the U.S. (48). There was good correlation between the 6 tests, with tests containing similar tasks showing greater correlation. Measures which tested health literacy, such as the NVS, METER, S-TOFHLA, had higher correlation with each other than with measures of self-reported health literacy, such as screening questions of health literacy. However instruments varied widely in the percentage of participants categorised as having limited health literacy; the S-TOFHLA classified the lowest percentage (7.5%) and the NVS the highest percentage having limited health literacy (48%).

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More comprehensive measures of health literacy, reflecting the broader range of competencies required to maintain health as described in chapter 1, include the US Health Activity Literacy Scale (HALS) and the European Health Literacy Survey (HLS) (49, 50). The HALS was derived from an analysis of the National Adult Literacy Survey (NALS) and the International Adult Literacy Survey (IALS) and consists of 191 items which represent tasks and processes associated with health activities (49). The 5 domains of activity in HALS are health promotion, health protection, disease prevention, health care and maintenance, and systems navigation (table 1.2). The items in the HALS are pre-existing items from the NALS, which was administered to a large population sample (26,000). While the scale items test health related tasks and the scale was derived from a general literacy survey there is little detail on the scoring properties and therefore, the validity of the scale is unclear (49). Internal consistency of items in the scale was high with a Cronbach's alpha of 0.93.

A European consortium developed a new health literacy measure, the EU Health Literacy Survey questionnaire (EU-HLS-Q) in 2011 (51). This involved collaboration and conducting the survey in 8 European countries, namely: Austria, Bulgaria, Germany (North Rhine-Westphalia), Greece, Ireland, Netherlands, Poland, and Spain. Approximately 1,000 participants from each country completed the survey. Health literacy was measured using a health literacy survey developed from a conceptual model and definition developed by the European consortium, titled the EU-HLS-Q (36). The questionnaire has a subjective self-assessment approach and is completed by indicating on a 4 point Likert scale (very easy, fairly easy, fairly difficult, very difficult) the perceived difficulty of conducting health-related tasks in the domains of health care, disease prevention and health promotion. Skills or processes testing in the questionnaire are accessing, understanding, appraisal and application of health-related information. The consortium also administered the NVS test, a measure of functional health literacy as discussed above, in the survey. The general (overall) health literacy

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measure showed good correlation with the 3 sub-indices (health care, disease prevention & health promotion) as did the sub-indices with each other. There was a moderate correlation with the NVS, with a Spearman's Rho of 0.25 (table 1.2). The authors explained the limited correlation of the HLS-EU-Q with the NVS by pointing out the correlations they found with socio-demographic and socio-economic factors and the situational and contextual nature of the HLS-EU-Q items, many of which test higher order skills and health-related tasks, as is not the case with the NVS.

Some authors claim that the TOFHLA or the REALM is the 'gold standard' when it comes to measure health literacy. Justification for this claim is the observation that these 2 tests are the most frequently used measures in the literature. However a gold standard should mean the test is the best possible measure to identify a patient with a condition; it should be linked to a definition, which ideally is derived from a conceptual model of the condition. Experts should be involved in the process of creation of the instrument, the process involved should be clearly detailed and psychometric testing in a representative sample should be reported. In health literacy there are many issues that prevent the existence of a gold standard test at this time. For example as detailed in the definition section definitions are varied and over time have expanded to include background health knowledge, processes such as navigation of the healthcare system, not only individual capacities but also community capacities and a dynamic state which varies according to the healthcare domain, the nature of the healthcare system and across the life-cycle. With these more comprehensive definitions there are challenges to measuring the construct of health literacy, in terms of the need to use multiple and/or more comprehensive tools and the issue of feasibility. I agree with David Baker, who states of the TOFHLA and the REALM "neither instrument is a comprehensive measure of health literacy" but it is likely that these tools measure domains which reflect an individual's overall capacity (34). This belief is supported by the observation that, although the 2 tools measure

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different domains (the TOFHLA measures reading, comprehension and numeracy skills and the REALM measures word recognition and pronunciation) the 2 tests are highly correlated with a Spearman's correlation coefficient of 0.80. Shorter tools have the advantage of identifying individuals with limited health literacy skills in busy clinical environment. This has led to the development of shortened versions of existing tools e.g. the S-TOFHLA, new short screening tools e.g. the NVS and brief screening tools such as the SLS (table 1.2. These tools need to be used and tested in a broad variety of healthcare contexts, in different patient samples and against health outcomes to decide on their utility to identify those with limited literacy.

## **1.4 Population-based surveys on Health Literacy**

Evidence has been accumulating over the past 20 years of high rates of low or inadequate health literacy in many countries.

### *Health Literacy in the U.S.*

As mentioned in chapter 1 data on levels of health literacy in the U.S. stemmed from population studies on adult literacy in the 1990s and 2000s. In particular the 2003 National Assessment of Adult Literacy (NAAL) included items on health literacy and in 2006 the National Center for Educational Studies published data on health literacy from this survey (4). The NAAL survey was administered to 19,000 individuals in households and prisons across America, aged 16 years and older, and measured literacy (and health literacy) by completion of tasks in prose literacy, document literacy and numeracy literacy. The health literacy tasks were in the domains of health care and health information in clinical, preventive and navigation of the health system. The results showed that 53% demonstrated intermediate health literacy, 12% were proficient, 22% had basic health literacy and 14% were below basic health literacy. Health literacy levels were lower in the following groups:

- Men
- Black, Hispanic, American Indians/Alaska Native & multiracial Ethnic groups
- Adults who spoke a language other than English before starting school
- Adults 65 years and older
- Adults who did not attend or complete high school
- Adults living below the poverty threshold
- Adults who self-reported lower health status

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The findings listed were statistically significant at the 0.05 level. Of note in the group who had completed high school 15% had below basic and 29% basic health literacy, indicating that more than 40% had low health literacy.

### *Canada & Australia*

Data on levels of health literacy in Canada has been obtained from the International Adult Literacy Survey (IALS) conducted in 2003; findings on health literacy were presented in the report “Health Literacy in Canada: a Healthy Understanding” (52). These were derived from the health literacy 191 health-related tasks in the IALS, which were in the 5 domains of health care, disease prevention, health promotion, health protection and navigation of the health system. These are the items that were included in the Health Activity Literacy Scale by Rudd et al. (49). Just over 20, 000 Canadians, aged 16 years or older, participated in the IALS survey. Health literacy scores are grouped in 5 levels of health literacy, level 1 to 5. Level 3 on the health literacy scale is regarded as the “minimum required in order to participate fairly and fully in society” (52). The results showed that 60% of adult Canadians had a health literacy level of 1 or 2, indicating inadequate health literacy. Health literacy levels, compared with the national average scores, were lower in the following groups:

- Adults 66 years and older
- Immigrants who do not speak English or French
- Adults who are not employed

Similar findings were reported from the Australian Adult Literacy and Life skills Survey (ALLS) which reported on health literacy using a health-related scale similar to that used in the Canadian population study (53). The Australian study was conducted in 2006 in adults aged between 15 and 74 years. Health literacy levels were lower than level 3 (indicating inadequate

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health literacy skills) in 59% of participants. This rose to 83% of adults aged 65 years and older. Heath literacy levels were lower in the following groups:

- Adults aged 65 years and older
- Adults who completed year 12 of education
- Adults who did not engage in educational participation in the previous 12 months
- Adults who were not employed
- Immigrants from non-English speaking countries

Similarly in an Australian population sample (N= 2,824) Adams et al. found that a high likelihood of inadequate functional health literacy, as measured with the Newest Vital Sign (NVS), was more common with increasing age, lower education attainment, lower annual income, poorer self-reported health status and in those who were born outside of Australia, England, Ireland and New Zealand (54).

## *Europe & Ireland*

Population-based data on health literacy in Europe has only been available in recent years following analysis of data from the 2011 English National Literacy and Numeracy survey (U.K) and in 8 European countries, including Ireland in the EU Health Literacy Survey conducted in 2011 (50, 55). Rowlands et al. analysed written health materials commonly used by the health service in England and categorised these according to the English Skills Qualification Framework in terms of text literacy and numeracy literacy. The authors linked this analysis to the findings of the population literacy survey (the English National Literacy and Numeracy Survey) and reported that 61% of UK adults aged 16-65 years found health materials commonly used in practice too complex to understand and use. Adults in the following groups were at highest risk of being below the health literacy

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threshold defined in this study (having the skills to fully understand and use 70% of the health material):

- Adults aged 45 years and older
- Adults for whom English is not the first language
- Adults whose annual income is less than £10, 000
- Adults from the top 5 most deprived areas in the U.K

Von Wagner et al. conducted a survey in 759 randomly selected British adults and measured functional health literacy, using the TOFHLA. They found the risk of having inadequate or marginal health literacy increased with age, being male, low educational attainment and low income (56).

The EU health literacy consortium developed a definition and health literacy survey (HLS-Q) in 2011. This consisted of self-reporting items on a 4 point scale (very easy, fairly easy, fairly difficult, very difficult) based on perceived difficulty of the items, covering the domains of health care, disease prevention and health promotion. There were 47 items which were subdivided into the 4 processes of “access”, “understand”, “appraise” and “apply” in relation to health relevant decision-making and tasks (50). The consortium conducted a health literacy survey in 2011 using the HLS-Q and the NVS (measure of functional health literacy) in 8 European countries (Austria, Bulgaria, Germany (North Rhine-Westphalia), Greece, Ireland, Netherlands, Poland, and Spain). There were approximately 1,000 participants, 15 years and older from each of the 8 countries, interviewed in the survey. Summary results were presented as a general health literacy index (data from all 47 items) and were categorised as inadequate, problematic, sufficient or excellent. The survey also reported on 3 sub-indices: a health care index (16 items), a disease prevention index (15 items) and a health promotion index (16 items). The consortium devised threshold scores for all 4 indices based on “the assessment of the likelihood of an individual to be confronted with excessively demanding situations” (21). The threshold for inadequate health literacy was 50% of total score of the index; the threshold between problematic and sufficient

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was set at 66%, and the threshold between sufficient and excellent was set at 5/6 or approximately 80 percent of the total score. In order to make comparisons more transparent scores of the 3 domains and the general (total) measure were brought to a uniform scale, with a total score of 50. Results from all 8 countries reported that 12% had inadequate health literacy and 35% problematic health literacy; the authors interpreted this as “nearly every second respondent shows limited health literacy” (50). Levels of inadequate and limited (inadequate + problematic) varied considerably between the 8 countries with percentages of inadequate health literacy ranging from 2% to 27% and limited health literacy from 29% to 62%. Results of the NVS showed that 21% of all participants (data from all 8 countries) had a high likelihood of limited literacy and 45% had either a high likelihood or possibility of limited literacy. Low levels of health literacy were associated with the following:

- Financial deprivation
- Lower self-assessed social status
- Lower level of formal education
- Increasing age (except for the Netherlands)

Doyle et al. present the EU-HLS, results from Ireland (21). There were 1,005 participants, average age was 45 years and there was a response rate of 69%. The results showed that 40% had limited health literacy, made up of 10.3% who had inadequate and 29.7% who had problematic health literacy. A further 38.7% had sufficient and 21.3% had excellent health literacy. Table 1.3 shows the mean and standard deviations in the 4 scales for total and for Irish respondents (50). From this data, Ireland scored above the mean in all 4 scales, with Irish respondents scoring highest in health care literacy skills and lowest in health promotion literacy skills, similar to findings in most of the other 7 European countries (50).

<b>Health Literacy Scales</b>	<b>Ireland Mean (SD)</b>	<b>Total Mean (SD)</b>
General Health Literacy Index	35.2 (7.8)	32.5 (9.1)
Health Care Literacy Index	36.3 (7.8)	34.& (8.3)
Disease Prevention Literacy Index	35.1 (8.5)	34.2 (8.8)
Health Promotion Literacy Index	34 (7.8)	32.5 (9.1)

Table 1.3: Summary results from the EU HLS survey (50).

There were significant differences in health literacy in the following groups:

- Educational attainment
- Income
- Gender (female higher than male)
- Self-perceived social class

In terms of functional health literacy as measured by the NVS, Ireland ranked joint fourth of the 8 countries (based on mean NVS scores). The mean NVS score was 3.6 for Ireland, with the range of means, among the 8 countries, of 2.6 to 4.5. NVS score is a test of numeracy and reading comprehension and correlations were significant with the following socio-demographic factors:

- Educational attainment
- Income
- Self-perceived social class
- Age (lowest in 76 years or older group)
- Employment status

In general items which tested understanding and response to instructions from a healthcare professional scored better than items where a judgement on health information was required, such as judging the

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reliability of health information reported in the media. For example 43.7% of respondents found it difficult to judge the reliability of information from the media while 85.7% of respondents found it easy to use information provided by their doctor to make decisions about their health.

These population studies confirm that limited health literacy is present in a significant percentage of populations, meaning many individuals have difficulty addressing health-related tasks. The studies also confirm that there is a social gradient in health literacy in the developed world. Those at increased risk include older adults, certain ethnic groups, those with lower socio-economic status, males, those with lower incomes and those with lower educational attainment. These factors are associated and in some studies have been shown to predict limited health literacy. They are also included in a conceptual model of health literacy by Paasche and Wolf, where they are linked with health literacy, as will be discussed in the next section (figure 1.2, page 38).

## 1.5 Health Literacy and Health Outcomes

As previously discussed in chapter 2 (Health Literacy concepts and definitions), in the public health outcome model for health promotion, health literacy is an intermediate outcome which can impact on the determinants of health, such as lifestyle factors and on the outcomes of health, measured as morbidity and mortality data, and social outcomes, such as quality of life and functional independence (27). Secondly, in this model, health literacy as an outcome can lead to “improved knowledge and understanding of health determinants, and changed attitudes and motivation in relation to health behaviour, as well as improved self-efficacy in relation to defined task” (27). There is some evidence from the literature to support a link between health literacy and these health promotion measures.

In the outcome model of health promotion, health and social outcomes are the end stage outcomes of health promotion, and determinants of health, such as lifestyle (modifiable) factors are intermediate outcomes. These determinants can be influenced by health promotion outcomes, such as health literacy. Therefore, according to this model of health promotion, it would be anticipated that health literacy levels are associated with both the determinants of health, and health and social outcomes. There is a growing body of research examining health literacy levels and these outcomes. The following details some of the key areas of research and findings in this field.

### *Disease prevention measures*

A review by Castro-Sánchez et al. on health literacy and infections and infection-related behaviour (vaccinations) found that there was a small number of studies in this area reporting that limited or insufficient health literacy was associated with reduced adoption of protective behaviours such as immunization, and an inadequate understanding of antibiotics (57).

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Berkman et al. report a number of studies which found significantly lower rates of uptake of mammography screening for breast cancer in the age group 65 years and older, who had basic/ marginal or low functional health literacy (5). Similarly Berkman et al. report a number of studies in community dwellers which found significantly lower rates of receipt of the influenza vaccine in those with low functional health literacy. Of note studies that examined health literacy and other screening tests, such as the Papanicolaou (pap) test and colon cancer screening, reported mixed results, with some reporting associations between health literacy and uptake rates and others reporting no association (5).

### *Lifestyle factors*

Two studies examined health literacy and levels of physical activity and found no difference in physical activity by health literacy level (5). After adjusting for confounders von Wagner et al. found a small but statistically significant higher likelihood of eating 5 portions of fruit or vegetables a day in those with higher levels of functional health literacy (56). A study on health literacy and lifestyle in 489 adults, 65 years and older, did not find that health lifestyle composite measure (exercise, nutrition and health responsibility) was higher in those with adequate health literacy (58). In relation to obesity Berkman et al. report on 4 studies, which did not adjust for confounders; results were mixed with 2 studies reporting differences in BMI by health literacy level and 2 studies finding no differences (5). Berkman et al. report that there is insufficient evidence to show a link between low health literacy and smoking or alcohol consumption (5).

*Taking Medication, following health instructions*

A low level or limited health literacy has been shown to be associated with poorer medication adherence, task completion, such as taking medication correctly and interpretation of labels and health messages. Berkman et al. summarise a number of studies on medication adherence and functional health literacy in patients with HIV; these studies reported significantly higher rates of non-adherence to HIV mediations in those with low health literacy (5). These findings were significant after adjusting for confounding factors such as race, gender, education, income and number of medications. Bailey et al. found that parents attending a paediatric clinic, had significantly higher rates of misinterpreting prescription label instructions if they had low or marginal functional health literacy as measured by the REALM test (59). This was after adjusting for age, gender, ethnicity and school attainment. Paasche-Orlow et al. examined health literacy levels in 73 asthmatic inpatients and, after adjusting for age, gender, education, income and history of near fatal asthma, found lower probability of mastery of metered dose inhaler technique in those patients with inadequate functional health literacy, as measured with the S-TOFHLA (60). Yin et al. reported that parents with a high likelihood of limited health literacy (NVS) were more likely to inaccurately measure liquid medication doses compared with parents with adequate health literacy; odds ratio was 1.7 and there were 302 participants (61). Waldrop-Valverde et al. carried out a cross-sectional study in 155 adults with HIV and found that higher health literacy, measured with the TOFHLA test, was associated with better medication taking skills, a composite measure which included interpretation of medication labels, counting a week's supply of medication and determining missed doses (62). Berkman et al. summarised results from a number of studies which reported lower rates of correctly take one's medication in patients with low health literacy (5). The review also summarises studies which reported higher rates of misinterpreting one or

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more prescription instructions, in patients with inadequate functional health literacy.

### *Knowledge of disease*

One study in newly diagnosed prostate cancer patients, with a mean age of 67, who had low functional health literacy, as measured with the Rapid Estimate of Adult Literacy in Medicine (REALM), had a more limited understanding of prostate cancer knowledge, questioning their ability to effectively participate in shared decision-making of complex information regarding treatment and quality-of-life issues (63). Gazmararian et al. examined functional health literacy in 653 adults aged 65 years and older, who had at least one chronic illness and found, after adjusting for confounders, that those with inadequate health literacy knew significantly less about their chronic illness than those with adequate health literacy (64). Participants had one or more of the following chronic illnesses: asthma, diabetes, hypertension or congestive heart failure. (63). Powell et al. found a significant relationship between functional health literacy, as measured with the REALM, and diabetes disease knowledge in 68 patients with type 2 diabetes (65). In a study in 102 patients with diabetes, Mancuso reported a significant relationship between functional health literacy, as measured with the S-TOFHLA, and diabetes knowledge (38).

### *Chronic disease prevalence*

A number of studies examined rates of chronic diseases in those with low compared to adequate health literacy. These are summarised in the systematic review of health literacy and outcomes by Berkman et al. (5). The largest study, in 23,889 participants, was linked to the National Adult Literacy Survey (NALS) (66). The authors reported that lower health literacy was significantly associated with having a long-term illness. Following adjustment for literacy levels, education and race were no longer significantly associated with having a long term illness, which may indicate

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that literacy is an important factor in the link between health inequalities and health outcomes. Sudore et al. examined health literacy in 2,512 community-dwelling older people and found higher levels of limited functional health literacy, as measured by the REALM in those with diabetes and depression (67). Wolf et al. examined health literacy, using the S-TOFHLA in 2,923 older community dwellers and found inadequate health literacy was associated with higher rates of diabetes and heart failure but not with higher rates of hypertension, coronary heart disease, bronchitis, asthma, arthritis, or cancer (68) . By comparison the researchers found no association between marginal health literacy and chronic illness prevalence. In a population study by Adams et al. people with inadequate functional health literacy, measured by the NVS, were more likely to have diabetes, cardiac disease or stroke (54). McNaughton et al. screened 228 Guyanese patients attending an emergency department for functional health literacy and random plasma glucose and point of care HbA1c. Almost half of those screened had low health literacy. They reported a significantly higher percentage of those with low health literacy having undiagnosed diabetes compared to those with adequate health literacy, namely 7.1% and 1.6% respectively (69).

### *Hospital stay and readmission rates*

Baker et al. and Howard et al. both reported a significant relationship between functional health literacy, as measured by the S-TOFHLA, in 3,260 community dwellers, and rates of inpatient service use and emergency department visits (5). Berkman et al. also report a number of smaller studies which found higher rates of emergency department use and/or hospitalisation in elderly patients attending outpatient services, in attendees at inner city hospitals, and in attendees at a public clinic (5). Mitchell et al. examined unplanned hospital re-utilisation rates, either emergency department and/or readmission rates, in the 30 days post discharge from hospital, and found that low functional health literacy, as

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measured by the REALM, was a significant independent risk factor for 30-day re-utilisation (70).

### *Health status and health literacy*

A number of studies have looked at the relationship between health literacy and health status; findings are supportive (though not shown in all studies) of an association between lower limited health literacy and lower health status (in many studies measured as self-reported health status) (5). Some of the studies adjusted for confounders such as age, race, gender and/or income while others did not. The EU HLS survey found a significant association between lower health literacy and lower self-assessed health status (unadjusted) (50).

### *Mortality outcomes and health literacy*

Baker et al. conducted a prospective cohort study on 3,260 Medicare community dwellers, aged 65 years and older, and found after adjusting for confounders such as age, ethnicity, education attainment and income, that functional health literacy independently predicted all-cause mortality and mortality from cardiovascular disease (71). Similarly Sudore et al. conducted a prospective study on 2,512 elderly community dwellers and after adjusting for age, ethnicity, socioeconomic status, health-related behaviours, co-morbidities and access to health care reported that limited functional health literacy was independently associated with all-cause mortality (72).

### *Hypertension*

A number of studies examined hypertension control and health literacy with mixed results (5). One study in patients with elevated blood pressure did not find higher levels of controlled blood pressure in those with limited compared to those with adequate functional health literacy. A second

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study found, after allocating patients to 5 categories of functional health literacy (using the S-TOFHLA), that those in the lowest category were less likely to have controlled blood pressure. Both studies controlled for a number of socio-demographic factors and comorbid health conditions.

### *Diabetes control, complications, and related outcomes.*

In their systematic review on health literacy and disease outcomes Berkman et al. reported mixed findings in studies examining the relationship between glycosylated hemoglobin (HbA1c) level and health literacy level (5). One study by Morris et al. in 1,002 diabetic adults found no relationship between HbA1c levels and functional health literacy level, after controlling for demographic characteristics, diabetes duration, diabetes education, medication, and alcohol use, as measured with the TOFHLA (73). Another study conducted in 102 patients with type 1 or type 2 diabetes also found no relationship between HbA1c and functional health literacy levels (measured using the TOFHLA) after controlling for diabetes knowledge, patient trust, depression, and performance of self-care activities (38). In contrast, a study in 68 patients with type 2 diabetes found, after adjusting for education, age, race, gender and treatment, significant differences in HbA1c between four functional health literacy levels (each one related to a high school grade equivalent), measured with the REALM (65). Schillinger et al. conducted a study in 395 patients with type 2 diabetes, where they measured functional health literacy using the S-TOFHLA (74). After adjusting for age, language other than English, health insurance and education, the researchers found that higher health literacy was related to better glycemic control and lower rates of retinopathy; furthermore the association between educational attainment and HbA1c was no longer significant when the data was adjusted for health literacy level (74). The fifth study, reported by Berkman et al. was conducted in Hong Kong in 149 patients with diabetes (5). After adjusting for gender, insurance, duration of diabetes and management of diabetes score, the

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researchers found higher functional health literacy levels in those patients who had better glycemic control. Kim et al. reported on functional health literacy levels and self-management skills, as measured by the S-TOFHLA and the Summary of Diabetes Self-Care Activities measure (SDSCA) respectively. The SDSCA is a valid self-report tool measure of how often a number of self-care, diabetes related tasks are performed per week. Lower health literacy was significantly associated with more self-reported diabetes complications but not with glycemic control (75).

### *Causal pathway linking health literacy to diabetes self-care and diabetes outcomes*

From the limited number of research papers discussed above there are mixed results on the relationships between diabetes and health literacy. It is likely that there are a number of variables operating directly or indirectly on diabetes self-care and outcomes and that health literacy may be a mediator of some of these variables or may act independently. For example Schillinger et al., in their research on health literacy in 395 patients in a low income population with diabetes, reported that education attainment was clinically and statistically significantly associated with better glycemic control (74). Similarly the authors found health literacy, as measured with the S-TOFHLA, had a significant association with glycemic control. Of interest the association between educational attainment and HbA1c was no longer significant when the data was adjusted for health literacy level. The association between health literacy and HbA1c, however, remained statistically and clinically significant after the data was controlled for education attainment. The authors conclude "These results suggest that in a population of low-income, ethnically diverse patients with diabetes, literacy at least partially mediates the observed relationship between education and glycemic control"(74). In this model literacy could be an outcome of education, which if inadequate, reflects difficulty in written and oral communications (prose, documentary and numeracy).

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The modern management of diabetes is modelled on self-care management by the patient and multidisciplinary management from the health care provider. Self-care involves understanding of illness, goals and self-care skills and motivation to reach these goals. Disease knowledge is essential for self-care; however low health literacy has been reported to be associated with poorer disease knowledge in diabetes and other conditions (38, 63, 65, 76). Understanding information about one's disease is also required for effective shared decision-making. Multidisciplinary care involves a more complex pathway in the patient's journey through the health care system i.e. navigation skills and the ability to access the system, effective communication and shared decision-making with multiple health care professionals. This care pathway places higher demands on the patient's literacy skills, in particular navigation and communication skills. There is some evidence that communication is better when patients with diabetes are cared for predominantly by their main care provider and it may be that better communication can lead to improved self-care (77).

Paasche and Wolf developed a conceptual model of linking limited health literacy to health outcomes, recognizing "both individual and system-level factors that affect access to health care, medical encounters, and self-care activities" (Figure 1.2) (78). At the level of access to health care, the authors point out that factors in persons with inadequate health literacy affecting access to health care include delays in making initial contact, negative feelings towards the healthcare provider and lower satisfaction with service provided compared to those with adequate health literacy. This can be augmented by a deep sense of shame and reluctance to disclose their problem with health care professionals, which has been reported on by

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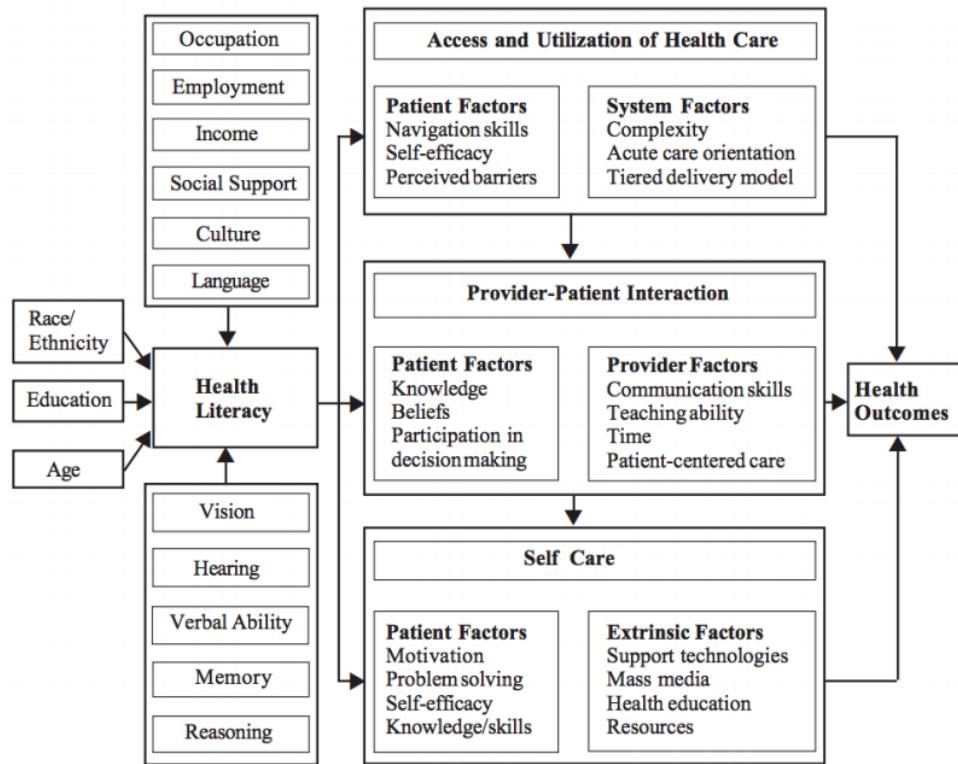


Figure 1.2 Causal pathways between limited health literacy and health outcomes.  
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Baker et al. (79). Health care system factors which can impact on ease of access to health care, by persons with limited health literacy, include ease of navigation of system and complexity of the health care system. At the level of patient-provider encounters, inadequate health literacy has been shown in some studies to be associated with less engagement with disease prevention measures, as discussed above under 'Disease Prevention'. Additionally inadequate health literacy may lead to the patient playing a more passive role in the provider-patient relationship; this can be due to the sense of shame, known associations with mental health issues and depression, and communication difficulties as discussed above (78). Input by the health care provider depends on allocated time, patient-centred communication techniques, such as the teach-back tool and general communication skills. Finally at the self-care level patients with limited health literacy have been found to have poorer disease knowledge, less

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adherence to medication instructions, more likely to have inaccurate knowledge about their medications, more at risk to misinterpret prescription instructions and poorer technique using medication-devices, such as metered inhalers (5). These factors contribute to self-efficacy and self-management skills. In diabetes Kim et al. reported on functional health literacy levels and self-management skills as discussed above (75). There was no difference in self-management skills between the group with adequate health literacy and the group with limited health literacy. Lower health literacy was significantly associated with more self-reported diabetes complications and poorer diabetes knowledge. Diabetes education was associated with improvements in glycemic control, self-management and diabetes knowledge in the group with adequate and the group with inadequate health literacy. At the self-care level, there is evidence from population studies that health information is frequently at too high a level for those with limited health literacy, making it difficult for them to understand and make appropriate health decisions (80). Additionally the nature of self-care involves patient understanding their symptoms and point of care readings e.g. glucometer readings, PEFR readings, blood pressure readings), interpretation of this information and with influence from family and social supports, making decisions and responding to improve care and outcomes. Paasche and Wolf point out that few of the currently available technologies supplying these point of care tests have been tested in those with limited health literacy (78). Finally this conceptual model of health literacy and outcomes includes the factors which feed into a person's health literacy level; these include factors known to be associated with health literacy, such as age, income, education attainment, employment, ethnicity, language. Additional factors include physical attributes such as vision and hearing, cognitive skills such as memory and reasoning skills, and social supports. The exact mechanisms and pathways of how these factors influence health literacy as an outcome and how, health literacy in turn, interacts with the variables above to influence self-management and health outcomes is poorly understood and

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more research in this field could lead to a better understanding of where resources can be targeted to improve outcomes for patients.

### **1.6 Health Literacy Interventions**

In recent years researchers are starting to address whether or not interventions designed to improve and simplify communication can ameliorate the impact of limited health literacy on health outcomes. This essential area of research is now gaining attention, as researchers, health care providers and health authorities are acknowledging the evidence that limited health literacy is common and limited health literacy is linked to poorer health outcomes. To date there is some evidence that interventions can affect a number of outcomes in diverse patient populations.

#### *Health outcome: Knowledge and comprehension*

Greene et al. and Peters et al. reported on the effect of alternative document design on comprehension in a randomised control trial (81, 82). There were 303 participants and half of these had low health literacy. Participants were asked to view information on fictitious consumer directed health plans; in the intervention arm the plans were presented detailing the common and unique features of plans, plans were presented in a framework detailing the advantages and disadvantages of each plan and plans detailed essential information only. Participants were asked 6 questions about the plans to test comprehension. The authors found that participants with low health literacy had significantly greater comprehension in the intervention arm compared with the control arm, when information was presented in a framework ( $p<0.05$ ), when only essential information was presented in the framework ( $p<0.01$ ) and when the essential information was presented first ( $p<0.01$ ).

Only a small number of studies have been reported on the effect of alternative numerical presentation of written information. Peters et al., in the study detailed in the preceding paragraph, also tested the effect of presentation of information on the quality of individual hospitals, where a higher number indicated a better quality (rather than a lower number).

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Compared with the control arm participants with low health literacy had greater comprehension in the intervention arm ( $p<0.001$ ). In participants with low numeracy skills ( $n= 1,047$ , 49% with low numeracy skills) Rocio Garcia-Retamero et al. reported greater comprehension when numerical information was presented using common denominators; the authors presented data to 1,047 participants on a fictitious drug with health outcomes; data was presented using common denominators in the intervention arm and different denominators in the control arm (83). Participants with low numerical skills had significantly higher comprehension in the intervention arm compared to those with low numerical skills in the control arm ( $p<0.01$ ). A study by Galesic ( $n=162$ ), in older adults, reported comprehension when data on genetic testing and probability of having a disease was presented using natural frequencies, reducing the number of computations participants were required to perform, in the intervention arm (84). They found improved comprehension in the intervention arm ( $P< 0.001$ ) compared with the control arm in participants with low numeracy skills.

Use of pictorial representation, additive and alternative, in printed health documents and effect on comprehension in individuals with low health literacy has been reported in the literature. Peters et al. studied the effect of adding symbols to information on hospital quality in their study on a fictitious consumer directed health plans and found that adding symbols did not improve comprehension in low health literacy participants (82). Another study ( $n=171$ ) examined the effect of adding icon arrays to numerical data in 3 fictitious treatment scenarios and reported improved comprehension in participants with low numeracy skills when icon arrays were added (85). Rocio Garcia-Retamero et al. in their study on the use of common denominators also examined the effect of adding icon arrays and found the addition of icon arrays improved comprehension in low numeracy participants when denominators of risk and risk reduction of treatment were different but had little effect when the denominators were

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the same (83). A study by Wright et al. 140 participants (41% had low numeracy skills) compared comprehension when data was displayed using grouped versus dispersed dots and found no significant differences in comprehension by display type in patients with health low literacy (86). Addition of dot displays (dispersed or grouped) did not improve comprehension in the low numeracy group.

Use of video or computer recording or slideshows in addition to or as substitutions of printed or verbal communication of health information has been reported in a small number of studies. Campbell et al. compared the effect of using informed consent forms in print, video and computerised forms in 233 adults (53% had low reading comprehension) and found no significant difference in recall of information (87). Bryant et al. (J urol 2009; 182(3): 1120-5) reported that use of a multimedia (print plus video) presentation of information on prostate cancer was associated with improved comprehension compared with print form only ( $p<0.001$ ) (88).

The effect of improved readability of documentation, using techniques such as use of larger font size, chunking of information, simplified language and using reduced number of words, has been reported in the literature. Greene et al. in a study on comprehension of a Medicaid health care plan chart explored the effect of using documentation with simplified language (89). Sample size was 122 and participants with low health literacy did not have significantly different levels of comprehension using the simplified compared with the standard chart. However the authors noted that the simplified chart was at a high school level of literacy and possibly required higher literacy skills than the level of literacy skills on those with limited health literacy. A study by Yates et al. compared a simplified advice sheet on head trauma and noted improved comprehension in those with low literacy with the simplified form ( $p<0.0001$ ) (90). In their study in 233 adults Campbell also compared use of a standard with a simplified consent form and did not find a significant difference in comprehension in those with low literacy (87).

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Gerber et al. reported the effect of a low literacy diabetes education multimedia intervention in 94 participants on diabetes knowledge and compared this to 89 participants in the control arm, who received usual care (91). The intervention utilised touch screen computers, in the delivery of lessons on diabetes education and were easy to navigate; they contained simplified text and lesson design was guided by Gagne's theory of learning in adults. Over 50% in each arm had low health literacy, as measured with the S-TOFHLA. The authors reported, in the subgroups with low health literacy, a greater reduction in HbA1c in the intervention group in those with poorer glycemic control ( $HbA1c >9\%$ ) compared with the control group, -2.1% versus -0.3%,  $p=0.04$ . Perceived susceptibility to complications, in those with low health literacy, increased significantly in those in the intervention group compared with the control group ( $p=0.02$ ). There were no differences between groups in self-efficacy, knowledge and medical care.

Kim et al. reported glycemic control and self-management behaviour in 92 patients with diabetes attending diabetes education classes, of which 23% had limited health literacy as measured with the S-TOFHLA (75). Glycemic control and self-management behaviour were not significantly different in the health literacy subgroups (adequate versus limited). Diabetes knowledge was significantly great in those with adequate health literacy. At 3 months post the intervention (diabetes education classes) self-management, diabetes knowledge and glycemic control improved in both groups (adequate and limited health literacy groups) with no significant difference in effect size between the groups. Wallace et al. conducted a similar study, measuring outcomes pre and post a diabetes education intervention, using a "literacy-appropriate diabetes education guide" (92). The guide was developed by an inter-disciplinary team of clinical researchers and was designed to be easily understood by patients, regardless of literacy level. It used plain language, a conversational tone, limited information and included pictorial presentations. Design was

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guided by social cognitive theory for behavioural change. There were 250 participants and 44% had limited health literacy, as measured by the S-TOFHLA. In the low literacy subgroup completion of action plans, self-efficacy and diabetes knowledge improved significantly, and diabetes distress reduced significantly when measured 3 months after the education programme compared with baseline (pre-intervention). In both of these studies the study design was pre and post intervention only.

Jay et al. conducted a study on the effect of a multimedia intervention to improve understanding of food labels in 56 patients attending a community health clinic for preventive care. Approximately 50% had limited health literacy as measured by the S-TOFHLA. The intervention consisted of a nutrition packs label pocket card, which contains a standard food label, colour-coded to indicate foods which are recommended and not recommended (or should be limited), and a video, using a question and answer format, explaining how to use the card. The control group received a publicly available food labels guide, which was printed in black and white. In those with low health literacy there was no significant change in nutrition knowledge at baseline and after nutrition education, in either the intervention or the control group.

Negarandeh et al. used pictorial representation and a teach back communication strategy in 127 patients with type 2 diabetes and low health literacy (93). There were 3 group, 1 control group and 2 intervention groups. They reported higher knowledge, adherence to medication and diet scores in the 2 intervention groups compared with the control group 6 weeks post intervention. However there are no baseline scores in these 3 outcomes.

### *Physician behaviour and Patient Self-efficacy*

Seligman et al. studied the effect of physician notification of the health literacy status of patients with limited health literacy on physician behaviour and patient self-efficacy (94). Sixty three physicians were

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recruited and randomised to the intervention and the control groups. There were 182 patients with type 2 diabetes recruited and 26% had limited health literacy, as measured with the S-TOFHLA. Compared with physicians in the control group, physicians in the intervention arm were more likely to use 3 or communication-enhancing measures with the patients with low health literacy, 31% versus 44% respectively,  $p=0.04$ . Communication-enhancing strategies including reviewing understanding of medications, referral to a diabetes educator and involving family members or friends. There was no significant difference in self-efficacy scores in patients in the control and intervention arms.

### *Preventive behaviour and emergency care utilisation*

In the area of preventive health care Ferreira et al. reported on uptake of screening for colorectal cancer in 382 participants in 2 clinical centres: one centre was the control and in the other centre physicians participated in education workshops on communication strategies suitable for busy clinics, which the authors describe as training in delivery of “short, powerful, and personal messages, that fit individual providers and patients” (95). Participants in the intervention clinic received a brochure and viewed a video on colorectal cancer screening. In those with low health literacy (tested with the REALM) screening completion was higher in the intervention centre than in the control centre, 55.7% versus 30.0% respectively,  $p=0.002$ .

DeWalt et al. reported on hospitalisations in patients with heart failure following an education intervention which was designed for low literacy patients and compared this to hospitalisations in patients who received usual care (96). Patients in the intervention arm had a 1-hour educational session with a healthcare professional; this employed a booklet designed for low literacy patients and included clinical scenarios, which were used to provide education on recognition of symptoms and signs of heart failure, performance of daily weight and dose adjustment of diuretic medication.

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Oral communication techniques felt to improve comprehension were also employed, such as teach back and engagement of the patient filling out the booklet. Health literacy was measured with the S-TOFHLA and 127 patients participated in the study. In the subgroup with low health literacy the incidence rate ratio (hospitalisation) was significantly lower in the intervention than the control group, incidence rate ratio 0.39, (95% confidence intervals 0.16, 0.91).

In summary there are a number of studies which explored the effect of print, verbal and multimedia materials adapted to improve comprehension in patients with limited health literacy. Design features of interventions that are likely to improve comprehension are presentation of essential information first, limiting non-essential information, presenting information where a higher number means better performance/outcome, adding icons to numerical data and adding video to verbal or printed materials. Mixed intervention studies which reduce emergency room visits and hospitalizations are those which focus on self-management and disease-management. These interventions can be recommended for use in patients with low health literacy and may contribute to improved health outcomes through their impact on patient-provider interaction leading to improved patient knowledge and improved provider communication, factors linking health literacy to health outcomes in the conceptual model by Paasche and Wolf (figure 1.2, page 38). With this conceptual model in mind future studies should target one or a number of factors in the model and there should be studies conducted not only on interventions which target patient interventions but also provider interventions. Further studies need to address methodology issues such as sample size and inclusion of sufficient numbers of individuals with low health literacy. Also confounders need to be addressed, as many of the reported studies do not give baseline socio-demographic characteristics of participants and do not adjust results for confounders. Qualities of interventions that positively affect health outcomes, such as theory driven interventions, piloting of interventions

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and the intensity of successful interventions should be incorporated into the design of future studies of interventions in low health literacy patients.

## **1.7 Health Literacy and Pregnancy**

To date little research has been conducted into health literacy levels in pregnant women or the factors associated with low or limited health literacy in this population. From the national population studies on health literacy, as discussed in detail in chapter 3, we do know that a number of factors are linked to limited health literacy, such as race, income and education, and it is likely that these same factors are linked to low health literacy in pregnant women.

Pregnancy outcomes are being audited in many countries and demographic characteristics are being identified that are linked with poorer outcomes. In the U.S., for example, African American women are more than twice as likely to receive no antenatal care, and have worse pregnancy outcomes, than non-Hispanic white women (97). Accessing antenatal care for the first time at a later gestational age or not at all is associated with less than a high school education in African American and other vulnerable groups, such as American Indian and Native Alaska Americans. In Canada infant mortality rates are higher in certain ethnic groups such as the Aboriginal population, where it is twofold higher than in the non-Aboriginal population (98). Luo et al. examined socioeconomic status and income in relation to outcomes of pregnancies in Quebec between 1991 -2000 (99). The researchers reported there were significant differences in rates of preterm births, small for gestational age, number of stillbirths, neonatal deaths and postnatal deaths across 5 income brackets, with rates highest in the lowest income group. After adjusting for maternal education level, rates of neonatal and postnatal death were no longer significantly different. Similarly significant differences in rates of preterm births, small for gestational age, number of stillbirths, neonatal deaths and postnatal deaths were reported in 4 education level brackets with rates highest in those with lowest level of education. Following adjustment for income the

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differences remained significant except in postnatal deaths. The size effect on pregnancy outcomes was greater for education than that for income. The authors noted that mothers in the poorer neighbourhoods were more likely to be unmarried, younger than 20 years, have a language other than English as their first language and not have completed high school. While this study did not measure health literacy, population studies have shown education attainment and income to be related to health literacy, which may be a mediator in pregnancy outcomes in these at risk populations. In Ireland the Perinatal Mortality report 2014, prepared by the National Perinatal Epidemiology Centre, reported 504 perinatal deaths nationally (100). Maternal characteristics of those with perinatal deaths showed that the minority groups of Irish traveller, Asian and Black were over-represented in the total perinatal deaths. The report also noted that first attendance at the hospital antenatal service was later (after first trimester) in the majority of women with a perinatal death. Finally unemployment rates were higher in the group of mothers with a perinatal death (14.2%) compare with the overall rate of unemployment of all mothers (4.6%). There is no reference to health literacy in the report. Both unemployment status and disadvantaged ethnic minority groups, both of which are over-represented in the group of Irish women experiencing a perinatal death, are linked to low health literacy. Studies to explore if low health literacy is present in this group of at risk women, and whether low health literacy is related to perinatal death, have not been conducted in Ireland.

## *Antenatal care*

Bennett et al. examined antenatal care in 202 African American women with low and adequate functional health literacy using the REALM (101). Fifty percent of the women had inadequate antenatal care, as measured by gestational age at time of first prenatal visit and total number of visits during pregnancy, and 16% had low functional health literacy. The authors did not find a significant difference in the number of women who had their

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first antenatal visit after the end of the first trimester or who had inadequate antenatal care between the low health literacy group and the group with adequate health literacy. From interviews and focus groups the researchers reported that “effective communication” described as “breaking it down” was viewed by the women with low and adequate health literacy as important and promoting attendance at antenatal care visits. It may be in this group of overall poor attendees at antenatal services, that factors other than health literacy, such as practice of effective reciprocal communication by healthcare providers, play an important role in antenatal care. Mojoyinola found a significant relationship between maternal health literacy and use of antenatal care and a healthy pregnancy, but not with pregnancy outcomes, in 231 pregnant women in Nigeria (102). Of note the measure used for health literacy was one the author developed and is not detailed in the publication. Kohan et al. reported on health literacy and antenatal care in 150 pregnant women attending an Iranian hospital (103). The measure used for health literacy was developed by the authors and tested for content validity and test-retest reliability. Results reported a significant difference in number of antenatal visits and gestational age at time of first antenatal visit between the “good health literacy” group and the “weak health literacy” group. Rates of iron deficiency anaemia were significantly different between the 3 health literacy groups, being highest in the low literacy group. Endres et al. examined the relationship between low functional health literacy in women with diabetes and pregnancy preparedness (104). The researchers used the S-TOFHLA and reported functional health literacy as low (if score was less than 30) or adequate (if score was 30 or higher). This varies from the threshold for adequate literacy established by the authors of the S-TOFHLA of 23 -36 for adequate health literacy. Of the 74 participants 16 (22%) had low functional health literacy. Pregnant women in the group with adequate functional health literacy were significantly more likely to have a planned pregnancy, to have had a prepregnancy consultation with an obstetrician or a diabetes

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specialist and to have attended an antenatal clinic at an earlier gestational age than the pregnant women in the low literacy group.

### *Pregnancy outcomes*

In the study by Endres et al. in pregnant women with diabetes, as described in the preceding paragraph, the following pregnancy outcomes did not differ significantly between the group with low health literacy and the group with adequate health literacy: mean gestational age at delivery, rates of vaginal delivery, rates of shoulder dystocia or neonatal intensive care admission rates. However the group with low functional health literacy had a significantly higher percentage of neonates with a birth weight greater than 4,000g, 63% versus 19% and were more likely to have been hospitalised during pregnancy than the group with adequate functional health literacy. Moynihan measured functional health literacy using the REALM in women with preterm deliveries and did not find a difference in health literacy levels with matched controls (delivery after 37 weeks gestation) (105). Level of inadequate functional health literacy was 56.4% overall and 62.5% and 49.6% in the preterm and control group respectively. Sample size was small with 56 women in the preterm group and functional health literacy was measured after delivery. The author did find a significant association of preterm delivery with low education attainment and low income. In the Iranian study by Kohan et al. the rate of premature delivery was significantly higher in the low health literacy group compared with the good health literacy group (103). In addition frequency of low birth weight was highest in the low health literacy group compared with the average and good health literacy groups. Of note the rate of Caesarean section was highest in the good health literacy group, which may reflect the higher birth weight (average birth weight 3,120g) in this group or other local factors and practices, compared with the other 2 health literacy groups. The authors reported no significant differences in APGAR score, infant death, meconium plaque or premature rupture of

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membranes and post-partum haemorrhage in the good, average and weak health literacy groups.

### *Postnatal care*

Ehrenthal examined postnatal care follow up and health literacy in women whose pregnancies were complicated by gestational diabetes (106). Functional health literacy was measured using the REALM (short form). The researchers reported that 81% of those who were referred for postnatal glucose testing attended for testing and that follow up was significantly more likely to be completed by women who had private insurance, were college educated, were married or had adequate health literacy.

The small number of studies on pregnancy and health literacy show that more research is needed in this field to determine the prevalence and define the population of pregnant women with low health literacy, and describe the demographic and clinical characteristics of this group. Health literacy is known to be associated with diabetes outcomes but it is not clear if there is a relationship between gestational diabetes outcomes and health literacy.

From the above it can be seen that there is limited data available on health literacy in pregnancy and all of the studies have captured functional health literacy only. This has influenced the design of this research in pregnant women at risk of GDM and data has been collected on both functional health literacy, using the Newest Vital Sign (NVS), and overall health literacy, using the EU Health Literacy Survey (using the EU HLS-Q).

## 1.8 Gestational Diabetes

Gestational diabetes (GDM) is defined as “any degree of glucose intolerance with onset or first recognition during pregnancy” (107). More than 90% of diabetes in pregnancy is gestational diabetes. Pregnancy is a physiological condition which is associated with increasing insulin resistance in the second and third trimesters. In the non-pregnant adult (type 2) diabetes, which is increasing in prevalence globally, there is a state of increased inflammation, associated with obesity and increase in visceral fat. This pro-inflammatory state leads to cytokine production by macrophages in the adipose tissue, which can affect post receptor insulin signalling. This results in alterations of insulin signalling resulting in increased insulin resistance (108). Pregnancy itself is a pro-inflammatory state and this leads to an increase in insulin resistance; in obese pregnant women there is a greater degree in insulin resistance, which can lead to GDM. In normal pregnancy, there is a 200-250% increase in insulin production in order to maintain euglycemia in the mother (109). Women who develop GDM have insulin resistance before pregnancy and the increase in insulin production is inadequate to compensate for the further increase in insulin resistance of pregnancy, leading to elevated plasma glucose levels consistent with GDM. In addition, hormone production of human placental lactogen and human placental growth hormone lead further to increased insulin resistance. The cellular mediators and pathways leading to increased insulin resistance in pregnancy are not clearly defined but are thought to involve tumour necrosis factor  $\alpha$  and adiponectin from adiposites.

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### *Diagnostic criteria of Gestational Diabetes*

The older diagnostic criteria of GDM were based on thresholds of glucose associated with risk of developing adult-onset (type 2) diabetes. For example, the O'Sullivan and Mahan criteria, first published in 1964, and used to define gestational diabetes for the subsequent 40 years, defined thresholds for diagnosis of GDM using a 100g oral glucose tolerance test (OGTT) with thresholds of fasting, 1 hour, 2 hour and 3 hour blood glucose levels of 5 mmol/L, 9.2 mmol/L, 8.1 mmol/L and 6.9 mmol/L respectively (110). To make a diagnosis 2 or more blood glucose readings that met or exceeded these thresholds were required. A follow up study by the O'Sullivan and Mahan group in these women diagnosed with GDM showed they were at greatly increased risk of developing diabetes at a later stage, with approximately 50% of the women developing diabetes within 10 years (110). The diagnostic criteria for GDM were revised a number of times as more research increased understanding of the significance of GDM and the associated higher risk of adverse outcomes, both perinatal and maternal. The current definitions, widely endorsed by international advisory groups, reflect the evidence linking GDM to adverse pregnancy outcomes, and the relationship of plasma glucose levels to these outcomes (table 1.4). The Hyperglycemia and Adverse Pregnancy Outcomes (HAPO) study has had a major influence on our understanding of GDM and on the diagnostic criteria currently in use (111).

### *The HAPO Observational study*

This multi-centre observational study was conducted from 2000 to 2006 in 15 centres in 9 countries; 23,316 pregnant women completed the study and all participants had a 75g glucose tolerance test (GTT) between 24 and 32 weeks of gestation, cord blood samples for measurement of glucose and C-peptide were taken at delivery. The primary outcomes measured were birth weight greater than the 90<sup>th</sup> percentile for gestational age (also

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known as large for gestational age), Caesarean delivery, neonatal hypoglycemia and cord-blood C-peptide levels greater than the 90<sup>th</sup> percentile. The authors found a linear relationship between maternal plasma fasting, 1 hour and 2 hour glucose levels and the primary outcomes of large for gestational age, primary caesarean section, neonatal hypoglycaemia and cord blood C-peptide levels. The adjusted odds ratios, for each increase in plasma glucose level by 1 standard deviation, were greatest for large for gestational age and cord blood C-peptide > 90<sup>th</sup> percentile. Odds ratios were statistically significant for all primary outcomes except for the association between neonatal hypoglycaemia and fasting and 2-hour plasma glucose levels. The International Association of Diabetes and Pregnancy Study Groups (IADPSG) convened a number of workshops and an expert panel between 2008 and 2010 to review the research on GDM, especially the data from the HAPO trial and data

	<b>Plasma Glucose Thresholds mmol/L</b>	<b>OGTT test</b>
IADPSG (2010)		
FPG	5.1	2 hour 75g oral glucose load
1-h plasma glucose	10.0	
2-h plasma glucose	8.5	
NICE (2015)		
FPG	5.6	2 hour 75g oral glucose load
2-h plasma glucose	7.8	

Table 1.4. Current broadly endorsed diagnostic criteria for GDM

from similar trials available at the time and presented new (lower) diagnostic criteria for GDM (table 1.4) (112). The IADPSG thresholds for fasting, 1 hour and 2 hour plasma glucose levels (table 1.4) are the mean plasma glucose levels at which there is an odds ratio of 1.75 of birth weight > 90<sup>th</sup> percentile, cord C-peptide > 90<sup>th</sup> percentile and percent body fat >

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90<sup>th</sup> percentile compared with mean plasma glucose readings of the study cohort in the HAPO trial. In order to make a diagnosis of GDM at least one of these thresholds must be met or exceeded. These diagnostic criteria have been endorsed by the American Diabetes Association (ADA) in 2011, the World Health Organisation (WHO) in 2013 and more recently by the European Board & College of Obstetrics and Gynaecology (EBCOG) and by the International Federation of Gynaecology and Obstetrics (FIGO) (113, 114).

The IADPSG expert panel also emphasized the subgroup of women who have pregestational diabetes first recognised in pregnancy, meeting the diagnostic criteria of diabetes, with higher plasma glucose levels, and that this subgroup are at higher risk of congenital anomalies and complications of diabetes, and need closer follow up during and after pregnancy. They labelled this subgroup as having “overt diabetes diagnosed in pregnancy” (112). The U.K National Institute for Health and Care Excellence (NICE) have published new diagnostic criteria in 2015 (table 1.4), which has a higher threshold of fasting glucose and will therefore diagnose fewer women with gestational diabetes than the IADPSG criteria. Of note the American College of Obstetrics and Gynaecology (ACOG) continue to recommend a 2 step approach, using a screening 1 hour 50g oral glucose challenge test, followed by a 3 hour 100g oral glucose tolerance test in those who fail the screening test. There is currently no gold standard for the diagnosis of GDM and there are a number of other diagnostic criteria in use around the world. This lack of a uniform set of diagnostic criteria poses a challenge in estimates of prevalence and comparison of studies in the field of GDM.

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### *Prevalence of Gestational Diabetes*

In a public health article on the prevalence of GDM Ferrara states that the “frequency of gestational diabetes usually reflects the frequency of type 2 diabetes in the underlying population” (115). The best prevalence data is from the HAPO study showing rates varying from 9% to 25%, with a mean of 17%, across all participating centres. Approximately 7% of pregnancies in the U.S. are complicated by GDM, ranging from 1 to 14%. Prevalence is higher in at risk populations; for example in the United Arab Emirates screening of 10,283 pregnant women using the IADPSG criteria yielded a prevalence of gestational diabetes of 37.7% (116). The prevalence of GDM in Australia has increased by 45%, from 1995 to 2005, from 3% to 4.4% (117).

The ATLANTIC DIP collaborators conducted universal screening for GDM between 2006 and 2009 in 5,500 pregnant women along the Atlantic coast in Ireland and reported a prevalence of 12.4% using the IADPSG criteria for gestational diabetes (118). The response was 74.1%, with a completion rate of 44.1%. Those who did not complete the study had a lower BMI and were younger than those who did participate. GDM occurred in 4.1% of pregnancies in the National Maternity Hospital in Dublin, Ireland in 2015 and 6.4% of pregnant women attending University Hospital Galway, Ireland in 2014 (119, 120). GDM occurred in 6.6% of pregnant women attending the maternity services at University Hospital Galway in 2013 (121).

This research was conducted in Galway University Hospital, Ireland, one of the centres of the ATLANTIC DIP programme, where the current practice is selective screening of women with risk factors, using the IADPSG criteria for diagnosis of GDM as determined by the Health Service Executive (HSE) recommendations.

*Adverse Outcomes associated with Gestational Diabetes*

*Perinatal adverse outcomes*

The hyperglycaemia-hyperinsulinemia hypothesis or more commonly known as the Pedersen hypothesis proposes that maternal hyperglycemia leads to an exaggerated foetal insulin response during pregnancy. This hypothesis states “maternal hyperglycaemia results in foetal hyperglycaemia and, hence, in hypertrophy of foetal islet tissue with insulin-hypersecretion. This leads to greater foetal utilization of glucose. This phenomenon will explain several abnormal structures and changes found in the newborn” (108). Outcomes such as foetal macrosomia and large for gestational age, which can lead to increased birth complications, such as shoulder dystocia and delivery by Caesarean section, and neonatal hypoglycaemia can be understood in light of this hypothesis. Adverse perinatal outcomes, which have been shown to occur significantly more frequently in GDM are large for gestational age, macrosomia, neonatal hypoglycaemia, shoulder dystocia and admission to neonatal intensive care unit (111, 118, 122). A literature review by Mitánchez on neonatal outcomes in GDM concluded that there is a slight increased risk of congenital malformations in GDM, with odd ratios ranging from 1.06 to 1.5, compared to the general population, with the risk associated with overt diabetes diagnosed in pregnancy, higher plasma glucose levels especially fasting plasma glucose levels, earlier gestational age at time of diagnosis of GDM and maternal obesity (123). Malformations are mostly cardiovascular, musculoskeletal and central nervous system defects. Although shoulder dystocia is increased in GDM and rates reduce with treatment of GDM, birth injuries and brachial plexus injuries are rare in GDM (123). Risk of perinatal death is increased in GDM and is likely to be associated with undiagnosed type 2 diabetes (123). However, while a WHO systematic review reported a clinically significant relative risk of 1.55, this did not reach statistical significance (124).

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In Ireland the ATLANTIC Diabetes in Pregnancy (ATLANTIC DIP) programme which involves 5 antenatal centres along the Irish Atlantic coast reported that women with GDM (diagnosed using the IADPSG criteria) had statistically significant greater prevalence of premature delivery, large for gestational age infants, neonatal intensive care unit admission and neonatal hypoglycaemia (table 1.5) (118). Prevalence of macrosomia was higher in the group with gestational diabetes compared with the group with normal glucose tolerance, 23.9% versus 17% but did not reach statistical significance. The odds ratios and 95% confidence intervals (CI) were 1.7

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### Prevalence of neonatal outcomes in ATLANTIC DIP study 2006-2009\*

Variable	NGT	GDM	p value	OR (95% CI)
Premature delivery	223 (4.8)	47 (7.1)	0.002	1.7 (1.1-2.6)
LGA	751 (16.2)	149 (22.6)	<0.0001	1.3 (1.0-1.7)
Neonatal intensive care unit admission	419 (9.1)	170 (26.0)	<0.0001	3.9 (3.0-5.1)
Neonatal hypoglycemia	28 (0.6)	16 (2.4)	<0.0001	3.4 (1.3-9.0)

Table 1.5 Adverse neonatal outcomes in GDM \*Data from O'Sullivan et al (118)

NGT, normal glucose tolerance

(95% CI 1.1-2.6) for premature delivery, 1.3 (95% CI 1.0-1.7) for large for gestational age, 3.9 (95% CI 3.0-5.1) for neonatal intensive care unit admission and 3.4 (95% CI 1.3-9.0) for neonatal hypoglycaemia.

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### *Maternal adverse outcomes*

Adverse maternal outcomes associated with GDM are pre-eclampsia, hypertension, caesarean section and risk of type 2 diabetes (111). There is an increased risk of preeclampsia in pregnancies complicated by GDM. A systematic review by the WHO pooled the results of 4 studies which used the 1999 WHO diagnostic criteria for gestational diabetes (75g OGTT with plasma glucose thresholds of 7.0mmol/L for fasting plasma glucose and 7.8mmol/L for 2-hour plasma glucose readings)(124). There was a positive and significant association between GDM and risk of preeclampsia with a relative risk of 1.69 (95% confidence interval 1.31-2.18; p < 0.001). Pooled results from 3 studies using the IADPSG diagnostic criteria similarly showed a significant association with a relative risk of 1.71 (95% confidence interval 1.38-2.13; p < 0.001). The WHO systematic review reported a significant positive association between caesarean section and GDM. Four studies using the 1999 WHO diagnostic criteria reported a pooled relative risk of 1.37 (95% confidence interval 1.24-1.51; p<0.001) and 3 studies using the IADPSG diagnostic criteria had a pooled relative risk of 1.23 (95% confidence interval 1.01-1.51; p=0.03).

As described in the section on diagnostic criteria for GDM, there is a long association between prior GDM and risk of developing type 2 diabetes. This was recognised as far back as 1917, when Elliot P. Joslin described a case of hyperglycemia in pregnancy, which resolved after pregnancy but 9 years later the patient developed diabetes (125). Kim et al. carried out a systematic review of GDM and the risk of type 2 diabetes in 2007 (126). Twenty eight studies were included in the systematic review and the conversion rate to type 2 diabetes ranged from 2.6% to 70%, in those screened between 6 weeks and 28 years post-delivery. Of note the rates of follow up testing varied from 38% to 100% in the studies i.e. between 38% and 100% of women with gestational diabetes had a follow up glucose tolerance test. Cumulative risk of developing type 2 diabetes is greatest in the first 5 years and then the risk increases more slowly after 10 years. The

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authors reported fasting plasma glucose, 1-hour and 2-hour plasma glucose levels, as part of an OGTT performed during pregnancy predicted risk of developing type 2 diabetes. For example one study found that a fasting glucose level greater than 6.0mmol/L was associated with an 11-fold increased risk for future diabetes. Pre pregnancy BMI and average BMI during pregnancy were found to be associated with risk of conversion to type 2 diabetes in some studies but not in others. It was not possible to define the rate of progression to type 2 diabetes due to variations in diagnostic criteria used to define gestation diabetes and type 2 diabetes and variations in rates of retention and duration of follow up.

In Ireland the ATLANTIC Diabetes in Pregnancy (ATLANTIC DIP) programme, reported that women with GDM (diagnosed using the IADPSG criteria) had significantly greater prevalence of gestational hypertension, pre-eclampsia, polyhydramnios and delivery by Caesarean section (table 1.6) (118). Odds ratios were 1.5 (95% CI 1.0-2.0) for gestational hypertension, 1.1 (95% CI 0.7-1.8) for pre-eclampsia, 2.5 (95% CI 1.2-5.2) for polyhydramnios and 1.3 (95% CI 1.0-1.6) for Caesarean section associated with GDM.

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### Prevalence of maternal outcomes in ATLANTIC DIP study 2006-2009\*

Variable	NGT	GDM	p value	OR (95% CI)
Gestational hypertension	332 (7.5)	86 (13.8)	<0.0001	1.5 (1.0-2.0)
Pre-eclampsia	176 (4.0)	39 (6.3)	0.007	1.1 (0.7-1.8)
Polyhydramnios	37 (0.8)	21 (3.4)	<0.0001	2.5 (1.2-5.2)
Caesarean section	1,165 (24.9)	246 (37.2)	<0.0001	1.3 (1.0-1.6)

Table 1.6 Adverse maternal outcomes in GDM \*Data from O'Sullivan et al (118)  
NGT, normal glucose tolerance

### *Treatment of gestational diabetes and outcomes*

Treatment of women with GDM has been controversial as it was not evident until the 21<sup>st</sup> century that milder levels of carbohydrate intolerance

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found in most cases of GDM, as opposed to the higher levels of hyperglycemia in prepregnancy diabetes, respond to treatment and with benefits in terms of perinatal and maternal outcomes. Results from 2 randomised controlled trials have demonstrated that treatment of GDM lowered rates of adverse outcomes: the Australian Carbohydrate Intolerance Study in Pregnancy (ACHOIS) and the Maternal Fetal Medicines Unit Network trial (122, 127).

### *The ACHOIS randomised controlled trial*

The Australian Carbohydrate Intolerance Study in Pregnancy (ACHOIS) was conducted between 1993 and 2003 and randomised 1,000 women with gestational diabetes to usual antenatal care (control group) or received dietary advice, glucose monitoring and, if required, insulin therapy (122). Diagnosis of gestational diabetes was made if there was a positive 50g glucose challenge test (1-hour plasma glucose  $>7.8\text{mmol/L}$ ) and a fasting plasma glucose  $<7.8\text{mmol/L}$  or 2-hour plasma glucose level between 7.8 and 11.1mmol/L, in a subsequent 75g oral glucose tolerance test carried out at 24 – 32 week gestation. In the intervention group (treatment of GDM), compared with control group, there were significantly lower perinatal adverse outcomes (one or more of shoulder dystocia, bone fracture and/or nerve injury), lower mean birth weights, lower rates of large for gestational age infants and macrosomia, higher rates of induction of labour, lower rates of preeclampsia and less maternal weight gain during pregnancy (table 1.7). Rates of hypoglycaemia and neonatal hyperbilirubinemia requiring treatment were not significantly different between the intervention and the control group.

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<b>Maternal and neonatal clinical outcomes in ACHOIS intervention trial in GDM</b>				
<b>Outcome</b>	<b>Intervention group no. (%)</b>	<b>Routine-care group no. (%)</b>	<b>Relative risk (95% CI)</b>	<b>P value</b>
<b>Infants total no.</b>	506	524		
Adverse perinatal outcomes*	7 (1)	23 (4)	0.32 (0.14 to 0.73)	0.04
Mean birth weight +/- SD (g)^	3335+/- 551	2482+/- 660	-145 (-219 to -70)	<0.001
LGA	68 (13)	115 (22)	0.62 (0.47 to 0.81)	<0.001
Macrosomia	49 (10)	110 (21)	0.47 (0.34 to 0.64)	<0.001
Neonatal hypoglycaemia	35 (7)	27 (5)	1.42 (0.87 to 2.32)	0.16
Neonatal hyperbilirubinemia	44 (9)	48 (9)	0.93 (0.63 to 1.37)	0.98
<b>Women total no.</b>	490	510		
Induction of labour	189 (39)	150 (29)	1.31 (1.10 to 1.56)	0.002
Pre-eclampsia	58 (12)	93 (18)	0.7 (0.51 to 0.95)	0.02
Mean weight gain +/- SD (kg)^	8.1+/-0.3	9.8+/-0.4	-1.4 (-2.3 to -0.4)	0.01

Table 1.7 ACHOIS trial outcomes \*one or more of death, shoulder dystocia, bone fracture, nerve injury ^ mean difference between groups

## *The Maternal Fetal Medicines Unit Network RCT*

Landon et al. conducted a multi-centre randomised controlled trial, between 2002 and 2007, in pregnant women with mild GDM. Diagnosis of GDM was made using the Carpenter and Coustan criteria, with a 100g OGTT, which required 2 or more readings that met or exceeded the following thresholds: fasting plasma glucose 5.3mmol/L, 1-hour plasma glucose level 10.0mmol/L, 2-hour plasma glucose level 8.6mmol/L and 3-hour plasma glucose level 7.8mmol/L (127). Women in the intervention arm received formal dietary therapy and, if required, were treated with insulin; the control group had usual antenatal care. Nine hundred and fifty eight women were diagnosed with GDM and randomly assigned to the intervention or control arm of the study. Mean birth weight and body fat in grams were statistically significantly higher in the control group compared with the intervention group, as were the frequencies of macrosomia, large for gestational age and shoulder dystocia (table 1.8). The maternal outcomes that reached statistical significance between the control and intervention arm of the trial were: higher rate of preeclampsia, higher rate of caesarean section, greater mean weight gain during pregnancy and

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<b>Maternal and neonatal clinical outcomes</b>				
<b>Outcome</b>	<b>Intervention group no. (%)</b>	<b>Routine-care group no. (%)</b>	<b>Relative risk (95% CI)</b>	<b>P value</b>
<b>Infants total no.</b>	485	473		
Mean birth weight +/- SD (g)	3302+/-502.4	3408+/-589.4		<0.001
Mean fat mass +/-SD (g)	427+/-197.9	464.3+/-222.3		0.003
LGA	34 (7.1)	66 (14.5)	0.49 (0.32-0.76)	<0.001
Macrosomia	28 (5.9)	65 (14.3)	0.41 (0.26-0.66)	<0.001
Neonatal hypoglycaemia	25 (5.3)	31 (6.8)	0.77 (0.44-1.36)	0.32
Neonatal hyperbilirubinemia	43 (9.6)	54 ((12.9))	0.74 (0.49-1.12)	0.12
<b>Women total no.</b>	476	455		
Caesarean section	128 (26.9)	154 (33.8)	0.79 (0.64-0.99)	0.002
Pre-eclampsia	12 (2.5)	25 (5.5)	0.46 (0.22-0.97)	0.02
Mean weight gain +/- SD (kg) <sup>^</sup>	2.8+/-4.5	5.0+/-3.3	-	<0.001

Table 1.8 Maternal Fetal Medicine Unit Network RCT ^refers to weight gain from enrolment in the trial until delivery

higher mean BMI at delivery in the control group. Similar to the findings in the ACHOIS study there was no significant difference between the 2 groups in rates of neonatal hypoglycaemia or hyperbilirubinemia requiring treatment. While shoulder dystocia occurred less in the ACHOIS and Landon studies, this did not reach statistical significance in either of the studies.

Horvath et al combined the data from both the ACHOIS and the MFMU trials in their systematic review and the odds ratio for shoulder dystocia was significantly reduced with treatment of GDM compared with usual care (128) . This analysis also looked at trials comparing less intensive with more intensive glycemic control in GDM and concluded that shoulder dystocia rates were lower in the intensive treatment but that an observed reduction in macrosomia was not significant (128).

## 1.9 Risk Factors for Gestational Diabetes

There is considerable overlap in the risk factors for GDM and type 2 diabetes. This is not surprising since both conditions are associated with insulin resistance and obesity. The 5<sup>th</sup> International Workshop Conference

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on Gestational Diabetes Mellitus recommended an assessment of all pregnant women at the first antenatal visit to determine the risk of developing gestational diabetes (129). Table 1.9 details risk factor categories and recommendations for screening reported by Metzger et al from this conference.

SCREENING FOR GESTATIONAL DIABETES MELLITUS*	
Risk Category and Clinical Characteristics	Recommendation for glucose screening
<u>High risk</u> (one or more of the following) Severe obesity Strong family history of type 2 diabetes Previous history of: gestational diabetes, impaired glucose metabolism, or glucosuria.	At initial antepartum visit or as soon as possible thereafter; repeat at 24-28 weeks if no diagnosis of gestational diabetes mellitus at that time
<u>Average risk</u> The patient fits neither the low- nor the high-risk profile	Between 24 and 28 weeks of gestation
<u>Low risk</u> (all of the following) Belongs to low-risk race or ethnic group No diabetes in first-degree relatives Age < 25 years Weight normal before pregnancy Weight normal at birth No history of abnormal blood glucose concentrations No prior poor obstetrical outcome	Not required

Table 1.9 Clinical screening for GDM \*Data are from Metzger et al

In Ireland, the Health Service Executive (HSE) recommends selective screening for risk factors at the first antenatal visit, with a 75g OGTT

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between 24 and 28 weeks in pregnant women who have one or more of the following:

- Family history of diabetes in a first degree relative
- Body mass index  $\geq 30\text{kg}/\text{m}^2$
- Maternal age  $\geq 40\text{years}$
- Previous unexplained perinatal death
- Current glycosuria
- Women on long term steroids
- Previous delivery of a baby weighing  $\geq 4.5\text{kg}$
- Polycystic Ovary Syndrome
- Polyhydramnios and/or macrosomia in existing pregnancy
- Ethnicity associated with a high prevalence of diabetes: (India/ Pakistan/ Bangladesh/ Black Caribbean/ Saudi Arabia/ United Arab Emirates/ Iraq/ Jordan/ Syria/ Oman/ Qatar/ Kuwait/ Lebanon/Egypt) (130)

This is similar to the NICE guideline on screening for GDM in the U.K. Screening for GDM in centres participating in the ATLANTIC DIP program is according to the ‘Clinical Guidelines for the Management of Diabetes in Pregnancy’, 3<sup>rd</sup> edition, published in August 2015 (131). The maternity hospital in University Hospital Galway, where the study participants were recruited for this research is a participating centre and follows this screening protocol. Table 1.10 shows the details of this screening guideline.

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SCREENING FOR GESTATIONAL DIABETES MELLITUS*	
Risk Category and Clinical Characteristics	Recommendation for glucose screening
<u>High risk</u> <ul style="list-style-type: none"> <li>Severe obesity (BMI&gt;30)</li> <li>Prior history of gestational diabetes or</li> <li>delivery of large-for-gestational-age infant</li> <li>Presence of glycosuria</li> <li>Diagnosis of polycystic ovarian syndrome (PCOS)</li> <li>Strong family history of Type 2 Diabetes</li> <li>Ethnic subgroup (all ethnic subgroups)</li> </ul>	If one of more risk factors are present then should undergo a glucose tolerance test as soon as is feasible. If a woman is found not to have GDM at this initial screening, she should be re-tested between 24-28 weeks gestation.
<u>Medium risk</u> <ul style="list-style-type: none"> <li>Body mass index 25-30</li> <li>Maternal age &gt;30 years</li> <li>Long term steroids</li> <li>Previous unexplained perinatal death</li> <li>Polyhydramnios and/or macrosomia in existing pregnancy</li> </ul>	If one or more of these risk factors are present then should be screened at 24 to 28 weeks gestation
<u>Low risk</u> <ul style="list-style-type: none"> <li>Age &lt; 25 years</li> <li>Weight normal before pregnancy (BMI&lt;/=25)</li> <li>Caucasian</li> <li>No known diabetes in first-degree relatives</li> <li>No history of abnormal glucose tolerance</li> <li>No history of poor obstetrical outcome</li> </ul>	If ALL of these characteristics are present the screening is not required

Table 1.10 Screening for GDM (ATLANTIC DIP) (131)

This guideline is similar to the guideline of the 5<sup>th</sup> International Workshop Conference on GDM in table 1.9.

Pregnant women attending the antenatal service at the Department of Obstetrics and Gynaecology in UHG with one or more of the high or medium risk factors are invited for a 75g OGTT and a diagnosis of GDM

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is made according to the IADPSG criteria. It is anticipated that a higher prevalence of GDM is in this population of pregnant women attending for an OGTT than in the general population i.e. in excess of 12.4%, as found in the ATLANTIC DIP study (118). The ATLANTIC DIP programme reports that 37% of attending pregnant women are overweight (BMI 25-30) and 21% are obese (BMI>30). From this data it is probable that at least 58% of all pregnant women, attending the antenatal services in UHG, are invited for an OGTT (132). There is no data on health literacy levels in these pregnant women at risk of GDM, a number of whom will be diagnosed with GDM. This is the population of interest in this research. The next section will define the research question and aims of the research.

## Section 2. Methods

### 2.1 Research questions

Pregnant women at risk of GDM have higher rates of overweight and obesity. Currently it is estimated that 60% or more of pregnant women attending the antenatal services in University Hospital Galway are at risk of GDM. These women are at higher risk of adverse maternal and perinatal outcomes as described in the Introduction section. Health literacy levels, in this population of pregnant women, are unknown and is the focus of my research. Health literacy is associated with worse outcomes in chronic diseases, poorer adherence to medications and instructions, reduced ability to access preventive health services and other health-related activities. There is some evidence that prevalence of inadequate health literacy is higher in patients with diabetes and obesity.

#### *Research Questions*

1. What is the prevalence of inadequate health literacy in pregnant women at risk of GDM?
2. Is there an association between socio-demographic factors and health literacy in pregnant women at risk of GDM?
3. Is health literacy related to pregnancy-related factors (folic acid pre-pregnancy and breast-feeding) and adverse pregnancy outcomes in women at risk of GDM?

A number of adverse pregnancy outcomes, maternal and neonatal, were analysed by health literacy level. The outcomes selected were guided by those outcomes reported in the literature to be significantly associated with plasma glucose levels, GDM and/or pregnant women with risk factors for GDM. For example the HAPO observational study found a linear relationship between maternal plasma glucose levels and pre-eclampsia,

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gestational hypertension and Caesarean section delivery (111). The ATLANTIC DIP programme reported significantly higher risk of gestational hypertension, pre-eclampsia and delivery by Caesarean section in women with GDM compared with controls, as discussed in section 1.6 (118). The systematic review by Wendland et al. on GDM and pregnancy outcomes reported increased risk of pre-eclampsia and Caesarean section delivery in women with GDM compared with controls (124). A meta-analysis of pregnancy outcomes in women with polycystic ovary syndrome (PCOS), who are at increased risk of GDM, reported that PCOS is associated with a significant increased risk of GDM, pregnancy induced hypertension, pre-eclampsia and Caesarean section delivery (133). Based on these observations I selected GDM, gestational hypertension, pre-eclampsia and Caesarean section delivery adverse maternal outcomes in my health literacy analysis to test for associations with health literacy levels. Neonatal adverse outcomes which are reported to occur significantly more frequently in women with GDM compared with controls are LGA, macrosomia, neonatal hypoglycaemia, shoulder dystocia, prematurity and admission to neonatal intensive care unit ((111, 118, 122). Boomsma et al. in their meta-analysis of pregnancy outcomes in women with PCOS reported increased risk of prematurity and admission to a neonatal intensive care unit (NICU) (133). The association between GDM and small for gestational age (SGA) is not as strong: for example although O'Sullivan et al. found 60% higher levels of SGA in the GDM group compared with pregnant women with normal glucose tolerance in the ATLANTIC DIP study, this association was no longer significant following adjustments for insulin use and smoking (118). Most researchers include SGA as an adverse outcome in GDM studies, most likely in an effort to further explore the relationship between this adverse outcome with GDM, hypertensive disorders in pregnancy and obesity and other factors. SGA is a clinical relevant adverse outcome as infants with SGA are at significantly higher risk of neonatal morbidity and mortality and increased risk of dyslipidemia, hypertension and type 2 diabetes in later life (134). From this observations

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the following adverse neonatal outcomes included in the data analysis were prematurity, macrosomia, LGA, SGA, neonatal intensive care admission, neonatal hypoglycaemia and shoulder dystocia.

Finally I created a composite neonatal outcome and a composite maternal outcome, representing the presence of one or more adverse neonatal outcomes and adverse maternal outcomes, respectively. Composite outcomes have the advantage that more participants will have the composite than any of the individual adverse outcomes and can increase the power of a study, especially where outcomes occur in low numbers of participants. A number of research studies on pregnancy outcomes in women with diabetes create and use composite outcomes in their analyses (135-137). The individual outcomes included in the composite outcomes in these studies vary and there is no standard definition of a composite outcome of adverse pregnancy outcomes. I included all of the individual adverse maternal and individual adverse neonatal outcomes, included in the data analysis by health literacy levels, in the maternal and neonatal composite outcomes respectively.

## Methods

### 2.2 Study design

#### *Introduction*

This study was a prospective cohort study to determine health literacy levels in pregnant women at risk of GDM attending University Hospital Galway for a glucose tolerance test. This was a single-centre study. Recruitment and interviews took place between January 25<sup>th</sup> and April 1<sup>st</sup>, 2016. The consent form contained the participant's name, address and date of birth, which was necessary to record, in order that data on the results of the glucose tolerance test and pregnancy outcomes from patient and laboratory databases could be collected. Consent forms were coded and each participant was given a unique code number, which was used on all data collection forms. Therefore data collected was confidential and coded for participants. The participants' codes and identifying details i.e. names, home addresses and dates of birth were stored in an encrypted file and kept separate from all demographic, health literacy, laboratory and clinical data. The codes were accessed by a research assistant at the time of collection of laboratory and clinical data from the electronic databases. Data was treated confidentially and data collected was entered into the data spreadsheets (Excel 2013 and SPSS 22.0), which was linked to participants' study codes. In our participant information leaflet (PIL) we explained to each participant that data would be obtained from hospital information sources in a secure manner for the purpose of this study.

#### *Role of author in data collection*

On the day of attendance for an OGTT the author and 1 research assistant approached eligible patients and distributed the PIL and consent forms. Once consented the participant completed the demographic form. The author and research assistant interviewed participants individually in separate private rooms. At the time of the administration of the 2 health

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literacy measures neither the author nor the research assistant were knowledgeable of any of the details collected in the demographic form, including those factors known to be associated with limited health literacy, as detailed in section 1. This reduced the possibility of the author making assumptions or estimations as to the likelihood of a participant having good or limited health literacy. However it must be acknowledged that the ethnicity of the participant was unavoidably apparent to the author at the time of the administration of the health literacy measures; this is a known risk factor of inadequate health literacy. The tools used were structured and validated health literacy measures. The NVS (U.K.) is a direct test of reading, comprehension and numeracy literacy and there are 6 questions, which are asked of each participant. There is also a detailed instructions for administration and marking of responses to these 6 questions. The second health literacy tool is a self-reporting of a participant's perceived difficulty of health-related tasks and, by definition, there are no right or wrong answers. The author and the research assistant met in advance of the data collection to review and discuss the administration of both tools and agree on a standardised approach to administration. The author also had prior experience in administration of a health literacy measure (NVS) in a previous study. The aim was to increase the likelihood of administration of both tools under similar conditions. With 2 researchers present in the department each day of data collection it was possible to identify and approach all eligible pregnant women. If only 1 researcher had been present there would have been an increased risk of not identifying all eligible pregnant women. This may have introduced a degree of bias in the recruitment process. Finally all research is exposed to some bias and the aim must be to conduct the research in order to minimise bias and, thereby, maintain the validity of the research. For these reasons I decided that assisting in the recruitment and data collection on the day of the OGTT would keep the risk of bias lower than had I decided not to attend with the researcher. All other data from the electronic databases was collected by the research assistant, without any assistance from the author.

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### *Ethical approval*

An application was submitted to the Clinical Research Ethics Committee at Galway University Hospitals (GUH). The application is designed to ensure that all issues of ethical importance are addressed and that the research complies with the ethical principles for medical research involving human subjects according to the World Medical Organisation's Declaration of Helsinki (138). Ethics approval was granted in December 2015 (Appendix 3).

### *Health literacy measures*

The selection of 2 health literacy measures employed in my research was based on the literature review of measures of functional and general health literacy and the most recent population data on health literacy in Ireland. The selection was made at a time where there is no consensus on which measures of health literacy should be used in research settings. I decided to use 2 measures, a measure of functional health literacy and a general health literacy measure, to allow me to obtain a comprehensive overview of health literacy in my sample. This selection also has the advantage of a mixed methods approach, using a self-reported measure (HLS) and a direct test (NVS U.K.) of health literacy. Both measures selected, the N.V.S. and the HLS, have been employed in the recent European Health literacy survey, in which a population sample from approximately 1,000 Irish citizens participated in 2011. The NVS has been amended and validated in a U.K. sample, with input from content experts and has been validated against the TOFHLA (47). The terms and phrases employed in the U.K. version of the ice-cream nutritional label are similar to the everyday language in use in the U.K. and Ireland; for example the term "half a cup" as a serving size of ice cream, which is used in the original (American) version of the NVS has been replaced with U.K. versions with the term "100mls". As U.K. and Irish citizens use similar English terms and phrases in everyday language I selected the U.K. version of the NVS in this study. The HLS, described below has been developed by content experts

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and derived from a conceptual framework and definition of health literacy, and has been validated by the HLS consortium. It measures health literacy in the clinically relevant domains. Using these same 2 instruments allowed comparisons to be made between the results of the population data from Ireland and the results in my sample of women at risk of GDM.

### *Functional health literacy*

The Newest Vital Sign (NVS) was originally developed by Weiss et al. for a U.S. population as a test of functional health literacy, testing both reading comprehension and numeracy skills (23). More recently Rowlands et al. amended and validated the original NVS nutritional sheet and questionnaire for a U.K population and this U.K version of the NVS was employed in my study (47). This involved handing the participant a fictitious ice cream nutritional label to read and review. The participant is given time to read the label and then myself or my research assistant asked the accompanying 6 questions of the NVS. There is no time limit, as the participant can answer the questions in her own time. A participant can return to a previously answered question to change her answer if she requests to do so. A frequently asked questions sheet was supplied from Barry Weiss (personal communication) and guided the administration of the test. In general, the NVS takes approximately 3 minutes to administer. Each item has a score of 1 with a total score of 6. A score of 0 or 1 indicates high likelihood of limited health literacy, a score of 2 or 3 possible limited literacy, and scores between 4 or higher indicate adequate functional health literacy.

### *General health literacy*

The EU HLS –Q survey was developed by the EU Health Literacy Survey consortium in 2011 (50). This involved collaboration among 8 European countries, namely Austria, Bulgaria, Germany (North Rhine-Westphalia), Greece, Ireland, Netherlands, Poland, and Spain. The health literacy survey was developed from a conceptual model and a broad definition of health

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literacy in the domains of health-care, health promotion and disease prevention. Approximately 1,000 participants from each country completed the survey. There are 47 items in the questionnaire, which measure self-experienced or self-rated ability to perform health related tasks in different situations (Appendix 5). Each item starts with the question “On a scale from very easy to very difficult how easy would you say it is to....”. The subject has the choice to answer ‘very easy’, fairly easy’, fairly difficult’ and ‘very difficult’. If the subject answers (spontaneously) ‘don’t know’ then this can be recorded as the answer. Skills or processes tested in the questionnaire are abilities to access, understand, appraise and apply health-related information. Data from all 47 items gives a Health Literacy Index; data from items 1 to 16 inclusive give a Health Care- Health Literacy index (HC-HL), data from items 17 to 31 inclusive give a disease prevention health literacy index (DP-HL) and data from items 32 to 47 inclusive give a health promotion health literacy index (HP-HL). The authors of the EU HLS-Q describe the technical handing of the data, specifying the number of minimum number of valid answers for each index calculation and creation of standardized metrics to allow comparison between indices (table 2.1).

EU HEALTH LITERACY SURVEY – QUESTIONNAIRE (EU HLS-Q)				
	GEN-HL	HC-HL	DP-HL	HP-HL
<b>Items</b>	<b>Q1.1-Q1.47</b>	<b>Q1.1 –Q1.16</b>	<b>Q1.17- Q1.31</b>	<b>Q1.32- Q1.47</b>
<b>Number of Items</b>	47	16	15	16
<b>Minimum number of valid answers for index calculation</b>	43	15	14	14

Table 2.1 Health literacy indices and respective items in index calculations in EU HLS-Q (50). GEN-HL General Health Literacy Index, HC-HL Health-

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care Health Literacy Index, DP-HL Disease prevention Health Literacy Index, HP-HL Health promotion Health Literacy Index

For calculation of indices the answer for each item was scored as follows: 1 = very difficult, 2 = fairly difficult, 3 = fairly easy and 4 = very easy. All indices were standardized on a metric between 0 and 50, as described by the EU HLS consortium, using the following formula:

$$\text{Index} = (\text{mean}-1) \times (50/3)$$

Where:

**Index** is the specified index calculated

**Mean** is the mean of all participating items for each individual

**1** is the minimal possible value of the mean, as very difficult is scored with 1

**3** is the range of the mean (possible values are from 1 to 4)

**50** is the chosen maximum value of the new metric

The results of the HSL-Q were entered in the data spreadsheets using the scoring system and calculations of indices as described above, as specified by the EU HLS consortium. This provided a score for each participant (who meet the minimum of valid answers per index as stated in table 2.1) in each of the 4 indices, namely, Gen-HL, HC- HL, DP-HL and HP-HL.

### *Population*

Pregnant women attending antenatal services at the Department of Obstetrics and Gynaecology at University Hospital Galway are screened for risk of gestational diabetes according to the screening guideline for Gestational Diabetes from ATLANTIC DIP collaborators and the HSE National Guidelines(131). Briefly the guideline recommends clinical screening for risk factors at the first antenatal visit and pregnant women in the high risk and moderate risk categories are referred for an oral glucose tolerance test. High risk factors are obesity (BMI equal or greater than 30),

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prior history of gestational diabetes or delivery of large-for-gestational-age infant, presence of glycosuria, diagnosis of polycystic ovarian syndrome (PCOS), strong family history of Type 2 Diabetes and ethnic subgroup (all ethnic subgroups), and a pregnant woman with one or more of these risk factors is invited to undergo a glucose tolerance test as soon as feasible. If the pregnant woman is not diagnosed with GDM at this time, then arrangements are made to repeat the glucose tolerance test between 24-28 weeks gestation. Medium risk factors are overweight (BMI equal to or greater than 25 and less than 30), maternal age >30 years, history of long term steroid treatment, previous unexplained perinatal death, and polyhydramnios and/or macrosomia in existing pregnancy. Pregnant women with one or more medium risk factors are referred for an oral glucose tolerance test between 24-28 weeks gestation.

### *Participant recruitment*

Participants were approached on the day they attended for a glucose tolerance test at the phlebotomy services, in the Department of Obstetrics and Gynaecology at University Hospital Galway, informed of the study and given a participant information leaflet (PIL) to read (Appendix 2). Patients who agreed to participate signed an informed consent form and were given a demographic form to complete (Appendix 3).

On the morning patients were approached, confirmed that they were attending for a glucose tolerance test, given a brief explanation of the study and provided with a PIL attached to a clipboard to read. It was explained in the PIL and consent forms that participation was optional and if a patient did not wish to participate that this would not affect any aspect of her care in the department. Patients had the opportunity to ask any questions about the study prior to consent. Participants signed a consent form, which was countersigned by myself or my research assistant. The number of patients who did not consent or withdrew from the study were noted.

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### *Sample size*

In 2014 there were 2,914 births in University hospital Galway, which is an average of 56 births per week (120). According to the criteria in use for selective screening for GDM approximately 60% of pregnant women would be expected to be referred for an OGTT. This means that over a 9 week period it was estimated that approximately 300 women at risk of GDM would be referred for an OGTT. This formed the basis of the recruitment duration of approximately 9 weeks. The prevalence of limited health literacy from studies in pregnant women, as reviewed in section 1.5, was variable: Ehrenthal et al. reported 8.9% (measured with REALM, short form), Bennett et al. reported 16% (measured with REALM), Endres reported 22% (measured by the S-TOFHLA) and Moynihan reported 56.4% (measured with the REALM) (101, 104-106). It must be noted that Endres used a high cut-off for limited literacy of 30/36, which is at variance of that specified by the authors of the S-TOFHLA; no explanation was given by the authors for this. None of these studies used the NVS to measure health literacy and although significant correlations have been found between the measures used in these studies and the NVS (see table 1.2), there is also considerable variation in the percentage of participants categorized with limited health literacy according to the instrument used, varying from 7.5% using the S-TOFHLA to 48% using the NVS (48). The sample sizes in these studies were low and less than my estimated sample size: it ranged from 74 (Endres et al.), 169 (Moynihan), 202 (Bennett et al.) to 249 (Ehrenthal et al.). Another observation I made was that these studies were conducted in the U.S. and the socio-demographic characteristics of the pregnant women in these studies, as described in the article, is likely to be different to that of pregnant women in the West of Ireland. Based on these observations I concluded that there was poor validity of using prevalence data of limited health literacy in any of these studies to estimate a prediction of precision with my estimated sample size.

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### *Exclusion criteria*

- Pregnant women whose native tongue was not English and who had difficulty understanding spoken and/or written English.
- Pregnant women, whose native tongue was English but who had difficulty understanding written English
- Pregnant women who were under 18 years of age
- Pregnant women who lacked capacity to give informed consent

### *Consideration of exclusion criteria*

*Women whose native tongue was not English and who had difficulty understanding spoken and/or written English.*

It was necessary to exclude pregnant women who had difficulty understanding spoken and/or written English for a number of reasons. Both of the health literacy measures used in this study were in the English language and administration of these required the participant to understand communications in English, written and verbal. Both of the measures used were validated tools in the English language. The validity of the tools as measures of health literacy is maintained when the tools are delivered in accordance with the instructions of the authors. Introduction of additional steps in their administration, such as the employment of interpreters, would create opportunities for mis-interpretation and influence of interpreter factors/ biases and cultural influences on participants' responses. The researcher would not understand the communication between participant and interpreter and would not be in a position to identify these errors or respond to them. The author acknowledges that this exclusion criterion will lead to exclusion of some pregnant women, who because of their ethnic background, are at increased risk of both GDM and limited health literacy. This is the case as one of the screening criteria for risk of GDM is pregnant women from all ethnic subgroups (table 1.8) and women from ethnic subgroups who have

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communication difficulties in English will be excluded. This is a limitation of the study and is shared by most studies in the literature where health literacy measurement is conducted with validated tools which are usually only available in 1 or 2 languages.

### *Proxy consent*

Proxy consent would be required if pregnant women under the age of 18 years and/or who lack mental capacity to consent were included in the study. Those who lack capacity to consent are likely to be at higher risk of limited health literacy and exclusion of this group from the study may result in the finding of lower levels of limited health literacy than the true (measured and unmeasured) level in women at risk of GDM. Lack of capacity to consent can be due to visual impairment, hearing impairment, mental health conditions and/or intellectual disability, all of which may also impair health literacy skills. Pregnant women who lack capacity to consent would also have difficult in understanding written and/or spoken communication and these women would fall under a second exclusion criterion i.e. difficulty understanding English and be excluded from the study, and so, provision of proxy consent would not be a requirement in this study. The prevalence of women who lack capacity to consent to participate in research studies in pregnancy in Ireland is not known(139).

### *Data collection*

Once consented each participant completed the demographic form while in the waiting area. Participants were subsequently brought into a quiet room to administer the 2 health literacy measures. Consideration was taken in the timing of the interview for each participant, taking care that the participant's next blood sample in the glucose tolerance test was not scheduled in the next 30 minutes, thus ensuring that the glucose tolerance test was conducted according to protocol. The NVS (U.K.) was first administered, followed by the EU HLS. For the NVS the participant was

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handed the fictitious ice cream label and, following the instructions of the authors, the researcher explained the label, asked the participant to look at the label and to indicate when she was ready to answer some questions (appendix E). Explanations, test questions and responses to answers or queries were given in accordance with the NVS test instructions (140). The EU HLS was administered by explaining the nature of the survey i.e. no right or wrong answer and that answers reflect the participant's perceptions of the task difficulty. It was explained to the participant the answer options and each item started with the question "On a scale from very easy to very difficult how easy would you say it is to:...." (appendix F). The participant had the choice to answer 'very easy', fairly easy', fairly difficult' and 'very difficult'. If the subject answer (spontaneously) 'don't know' then this was recorded as the answer. The interview lasted approximately between 15 and 25 minutes. Interview duration was not recorded. Results of glucose tolerance tests, clinical data and pregnancy outcomes were accessed from the Hospital laboratory database (Patient Administration System), the Maternity electronic database (E3) and the DIAMOND ® database (records of those diagnosed with gestational diabetes) at a later date and entered in the datasheet.

### *Demographic Data*

The data collected included:

- Data required to describe in detail the demographic, social and economic characteristics of the study population
- Inclusion of factors which are known to be associated with health literacy
- Inclusion of factors which are known to be associated with GDM
- Inclusion of factors which are known to be associated with adverse pregnancy outcomes

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The demographic data was collected from the self-completed form by participants (appendix D) and from the maternity information database (E3), see next section.

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### 2.3 Clinical Databases

#### *E3 (Maternity Information database)*

This is a Maternity Information System, commercially available, and is used for all pregnant patients attending the Department of Obstetrics and Gynaecology in University Hospital Galway (141). All data is recorded electronically throughout the patient's journey from the first antenatal booking of pregnancy through to post-natal discharge. It is accessed at point of care which means that data is recorded in real time for each clinical encounter with the health service. For my research this system was accessed for 2 purposes:

- (a) to supplement the demographic data sheet collected from participants on the day of their glucose tolerance tests
- (b) collect data on participants' labour and pregnancy outcomes, both maternal and perinatal

#### *DIAMOND ® Diabetes database*

Each participant who received a diagnosis of GDM was referred directly to the joint diabetes antenatal clinic where she was jointly cared for by a multi-disciplinary team of obstetrician, diabetologist, diabetes nurse specialist, midwife and dietitian throughout the remainder of her pregnancy and up to the postnatal visit. The diabetes healthcare staff (doctors and nurses) recorded in real time all clinical data from each patient encounter from this point onward in the patient's journey. This is recorded in a commercially available electronic database in use for all patients with diabetes in University Hospital Galway, namely the DIAMOND ® database. This database is a web-based tool widely used in clinical practice in the management of diabetes and is commercially available from the U.K. company Hicom (Woking, UK). This captures demographic, clinical and laboratory data on each patient with diabetes attending our hospital. Access is restricted to institutional authorised users only. Our participants

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who were diagnosed with GDM had all data recorded from each clinical encounter in the DIAMOND ® database.

Data accessed was treated confidentially and data was recorded in the study data spreadsheets in coded form, with no identifying participant details. All datasheets were encrypted and stored in a password protected computer.

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### 2.4 Oral glucose tolerance test and IADPSG diagnostic criteria for GDM

The oral glucose tolerance test is a 75g 2-hour glucose tolerance test following a 12-hour overnight fast and smokers are asked to refrain from smoking during this time. The glucose tolerance test is scheduled in the morning. A fasting venous glucose sample is obtained in a fluoride oxalate bottle. Then the patient drinks 200 mls of solution, containing 113 mls of Polycal ® equivalent to 75g glucose. This is labelled time 0-hours. At 1-hour and 2-hours the venous samples are taken and samples are labelled as 0-hours, 1-hour, 2-hour glucose samples. Samples are sent to the local laboratory in University Hospital Galway for measurement of plasma glucose concentrations, reported as mmol/L. The protocol for screening and the glucose tolerance test are in Appendix A. Diagnosis of GDM is based on the IADPSG diagnostic points and is made if any one of the 3 plasma glucose readings are at or in excess of the thresholds of 5.1mmol/L, 10.0mmol/L, 8.5mmol/L for fasting, 1-hour or 2-hour measurements respectively (table 2.2). The IADPSG criteria are used at University Hospital Galway and have been endorsed by the ATLANTIC DIP Guidelines (112, 131).

Current Diagnostic criteria for GDM*	Plasma Glucose Thresholds mmol/L	OGTT test
IADPSG (2010)		2 hour 75g oral glucose load
FPG	5.1	
1-h plasma glucose	10.0	
2-h plasma glucose	8.5	

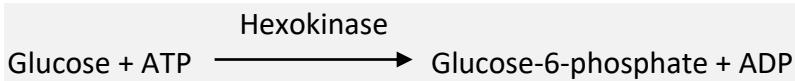
Table 2.2 IADPSG Diagnostic Criteria for Gestational Diabetes.

## Methods

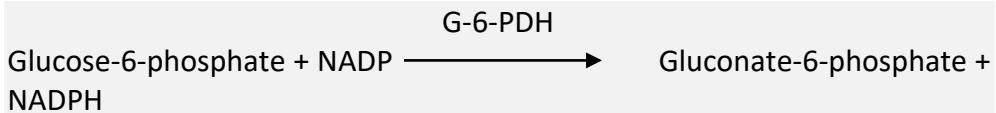
### *Glucose laboratory testing*

In University Hospital Galway the laboratory testing for the concentration of plasma glucose is performed using the commercially available GLUC 3 laboratory kit from Roche/Hitachi COBAS C systems. This is an enzymatic process involving the following 2 steps:

1. Hexokinase catalyses the phosphorylation of glucose to glucose-6-phosphate by ATP as follows:



2. Glucose-6-phosphate dehydrogenase (G-6-PDH) oxidizes glucose-6-phosphate in the presence of NADP to gluconate-6-phosphate as follows:



NADPH concentration is measured photometrically and this is directly proportional to the glucose concentration. Calibration frequency is in accordance with manufacturers' and local health service guidelines. Blood samples were taken in fluoride oxalate tubes and analysed within 4 hours of sample collection in our local laboratory in University Hospital Galway using this method.

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### 2.5 Maternal and Neonatal Biometric measures

Participants had weight and height measurements taken at the time of the first antenatal visit between 14 and 22 weeks. These measurements were taken by health care professionals in the antenatal clinic and recorded in the electronic record of the participant (E3, maternity information database). Height and weight data of participants was sourced from this database and was not measured by the author or assistant researcher. In the department weight is measured to the nearest 100g in light clothing, without shoes, and height is measured to the nearest 0.5cm using a calibrated digital (Seca 799 electronic column scales with BMI function, Seca Deutschland, 22089, Hamburg, Germany). using a calibrated digital weighing scales (Seca ® 799 flat scales) BMI in kg/m<sup>2</sup> was calculated and participants were categorised according to the World Health Organization (WHO) standards as underweight, normal, overweight or obese (142). Underweight is defined as a BMI of < 18.5 kg/m<sup>2</sup>, normal BMI is in the range 18.5 – 24.99 kg/m<sup>2</sup>, overweight BMI is in the range from 25 – 29.99 kg/m<sup>2</sup> and obese is 30 kg/m<sup>2</sup> or higher. Calculation of neonatal size for gestational age was done by referencing the child growth charts from the Child Growth Foundation (143). Large for gestational age (LGA) is defined as >90<sup>th</sup> centile for gestational age and small for gestational age as <10<sup>th</sup> centile for gestational age. Macrosomia is defined as birth weight 4kg or greater, regardless of gestational age.

In clinical practice weight and height measurements of pregnant women are taken at the first antenatal visit and BMI (kg/m<sup>2</sup>) is calculated. This is recommended by the NHS at the time of the first booking appointment (144). The gestational age at which measurements are taken vary, according to when the pregnant woman attends the antenatal clinic for the first time. From this observation it could be argued that pre-pregnancy BMI using pre-pregnancy weight would be more closely associated with adverse pregnancy outcomes than BMI at time of first attendance at the antenatal clinic. Studies on pre-pregnancy BMI have reported significant associations

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with adverse pregnancy outcomes, with researchers reporting significantly positive associations between pre-pregnancy BMI and pre-eclampsia, GDM, Caesarean section delivery, neonatal hypoglycaemia, admission to NICU and premature delivery (145, 146). However in practice there is a reliance on the patient to accurately recall her pre-pregnancy weight or BMI (132). Russell et al. examined the ability of a sample of pregnant women to accurate recall their pre-pregnancy weight by comparing patients' recall of their pre-pregnancy weight with measured and recorded pre-pregnancy weight in the patients' records. They found that there was a tendency to under-report pre-pregnancy weight (by a mean of 1.52 kg) and that approximately 1/3 could not recall their pre-pregnancy weight (147). These problems when using pre-pregnancy BMI in studies on associations between BMI and pregnancy outcomes have resulted in many researchers using BMI measured at the first antenatal visit as a surrogate indicator of pre-pregnancy BMI. Overweight and obese pregnant women, as defined by BMI at first antenatal visit (booking BMI) have been found to have significantly higher rates of pre-eclampsia, gestational hypertension, gestational diabetes, Caesarean section delivery, macrosomia, LGA, shoulder dystocia (148-150). Furthermore Natamba et al. found that self-reported pre-pregnancy BMI was significantly correlated with BMI measured at first antenatal visit (151). These findings support the utility of using BMI at booking as a surrogate for pre-pregnancy BMI.

## **2.6 Data Analysis**

Study datasheets with codes for variables and values were set up. A codebook was created with the key and explanations for codes used. Both Excel 2013 (Microsoft Office, Washington) and SPSS (Statistical Package for the Social Sciences- IBM, New York) version 22.0 were used in the data collection and analysis process. Health literacy data was entered, indices calculated in the case of the EU HLS-Q and data categorised in the case of the NVS according to authors' instructions (see EU HSL-Q and NVS (U.K.) sections above). Demographic data, collected on the day of interview and from the clinical databases, and laboratory results were similarly entered. 'Dummy' variables were created for variables used in the multivariable analysis. Monthly household income was converted to a binary variable of less than €1,350 and €1,350 or higher. Parental ethnic background was converted to one or both parents Irish or neither parent Irish. Education status was converted to the dummy variable of lower secondary education or less and third level education. Self-rated social status was converted to the dummy variable of low or middle/higher. Finally self-rated health was converted to the dummy variable of fair/poor or good/very good. These were the variables which were included in a multivariate analysis as they have been shown to predict health literacy in other studies (4, 49, 48, 53).

Categorical data on prevalence of limited health literacy was presented according to the categories described by the authors of the EU HLS-Q and the NVS. There are 4 categories in the HLS, namely 'inadequate', 'problematic', 'sufficient' and 'excellent' with defined threshold values. The European HLS consortium describe the process of the fixation of thresholds between these categories and the dichotomous grouping into limited and adequate health literacy groups. According to the authors "The guiding criterion for the fixation of thresholds was the assessment of the likelihood of an individual to experience health relevant tasks and situations as difficult."(50). For 'inadequate' health literacy a threshold of below score 26 was chosen, i.e. individuals with inadequate health literacy have at least

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rated 50% of the items as difficult or very difficult. The border between sufficient and problematic health literacy was fixed by a score value of 33, i.e. below 2/3 of the possible points that could be reached. This score coincides with the modus, median and mean of the distributions of the four indices, in the European HLS data from 8 countries, which lie between 33 and 34 points. The authors comment that the threshold between problematic and sufficient health literacy approximates important point estimators of the distribution of the indices. The cutting point between ‘sufficient’ and ‘excellent’ health literacy was designated by 42, which is equivalent to 5/6 of possible index points and approximately marks the point at which a participant finds 80% of tasks as very or fairly easy. The authors grouped ‘inadequate’ and ‘problematic’ to define limited health literacy, which equates to an index score of less than 33, indicating a person who is likely to have difficulty with at least 1/3 of health related tasks, reflecting the interaction between the individual’s competencies and situational complexities or demands, as reflected in the items in the EU HLS-Q. By contrast a person who scores 33 or higher is labelled as having adequate health literacy, and he/she is likely to have difficulty with less than 1/3 of health related tasks.

The NVS has 3 categories of functional health literacy, namely ‘adequate’ (score 4-6), ‘possibility of limited literacy’ (score 2-3) and ‘high probability of limited literacy’ (score 0-1). The NVS was validated by the authors (Weiss et al.) against the TOFHLA (23). A NVS score < 2 had a sensitivity of 72% and a specificity of 87% for predicting limited literacy and a score <4 had a sensitivity of 100% and a specificity of 64% for predicting limited literacy (TOFHLA <75, out of a total score of 100). There was a likelihood ratio of 0 for marginal/inadequate HL if NVS score was 4 or higher, which Weiss et al. interpreted as the threshold between adequate and limited literacy. Thus the categories of high likelihood of limited and possibility of limited literacy can be combined to form a limited literacy category. This guided the dichotomous grouping of the 3 categories of health literacy with the NVS in this study.

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Health literacy and demographic data analysis was conducted using the data from all participants. The data analysis on pregnancy outcomes and health literacy excluded twin pregnancies, as is the case in most studies examining pregnancy outcomes that are not addressing outcomes in twin and/or multiple pregnancies. Twin pregnancies are at increased risk of adverse maternal outcomes compared with singleton pregnancies. For example the relative risk of pre-eclampsia is 3.7, the relative risk of gestational hypertension is 1.3 and the relative risk of Caesarean section delivery is 2.4, compared with singleton pregnancies (152). Similarly adverse neonatal outcomes occur more frequently in twin pregnancies compared with singleton pregnancies; for example there is a 6-fold increased risk of prematurity and a 3-fold increased risk of admission to NICU compared with singleton pregnancies (152, 153).

Chi square test was used to explore for associations between the health literacy indices, expressed as dichotomous categorical variables and the demographic characteristics, pregnancy-related factors and pregnancy outcomes. A multiple regression analysis was conducted to determine if determinants of health literacy, such as education attainment, predicted health literacy in my study. This was explored in the general health literacy and functional health literacy indices. In addition, correlation between these health literacy indices was determined by calculating Spearman's correlation coefficient.

Finally both the HLS general index and the NVS measure scores were analysed as continuous variables. Parametric data was described as mean and standard deviation (SD) and non-parametric data as median and interquartile range (IQR). Between group differences were analysed using student T test for 2 groups and ANOVA for 3 or more groups for parametric data. For non-parametric data the Mann-Whitney U test was used to test for differences between 2 groups and the Kruskal-Wallis test when there were 3 or more groups in the independent variable.

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### Section 3. Results

#### 3.1 Participants' socio-demographic characteristics

All pregnant women, at the first antenatal visit to University Hospital Galway, are screened for risk of GDM according to the screening guideline from the ATLANTIC DIP collaborators and the National HSE guidelines (2010). Those at medium or high risk are referred for a 75g OGTT. All pregnant women at the time of their OGTT who met the inclusion criteria were invited to participate. Recruitment took place between 28<sup>th</sup> January and 1<sup>st</sup> April 2016. Over the recruitment period a total of 330 pregnant women attended for an OGTT of which 17 were ineligible because of poor English (figure 3.1). The 313 eligible pregnant women were invited to participate, of which 304 accepted, representing a response rate of 97.4%. Participants were consented and completed the demographic form (appendix 4). Interviews were conducted in quiet rooms in the department. The interviewers administered the NVS (U.K.) and the EU HLS – Q health literacy measures (appendices 5 and 6). Seven participants out of the 304 consented participants withdrew from the study, representing a completion rate of 97.7%. The 75g OGTT was carried out on the same morning and GDM was diagnosed according to the IADPSG (WHO 2013) criteria.

Figure 3.2 shows a breakdown of risk factors of participants according to the ATLANTIC DIP GDM screening tool. There was missing data on the following risk factors: presence of glycosuria, prior delivery of LGA infant, and BMI measure. In the case of 4 participants there was no recorded risk factor and so it was unclear as to the indication for an OGTT. For the remaining participants at least 1 risk factor was identified. From the data available 130 participants had 1 recorded risk factor, 11 participants had 2 recorded risk factors, 37 participants had 3 recorded risk factors and 13 participants had 4 or more recorded risk factors.

## Results

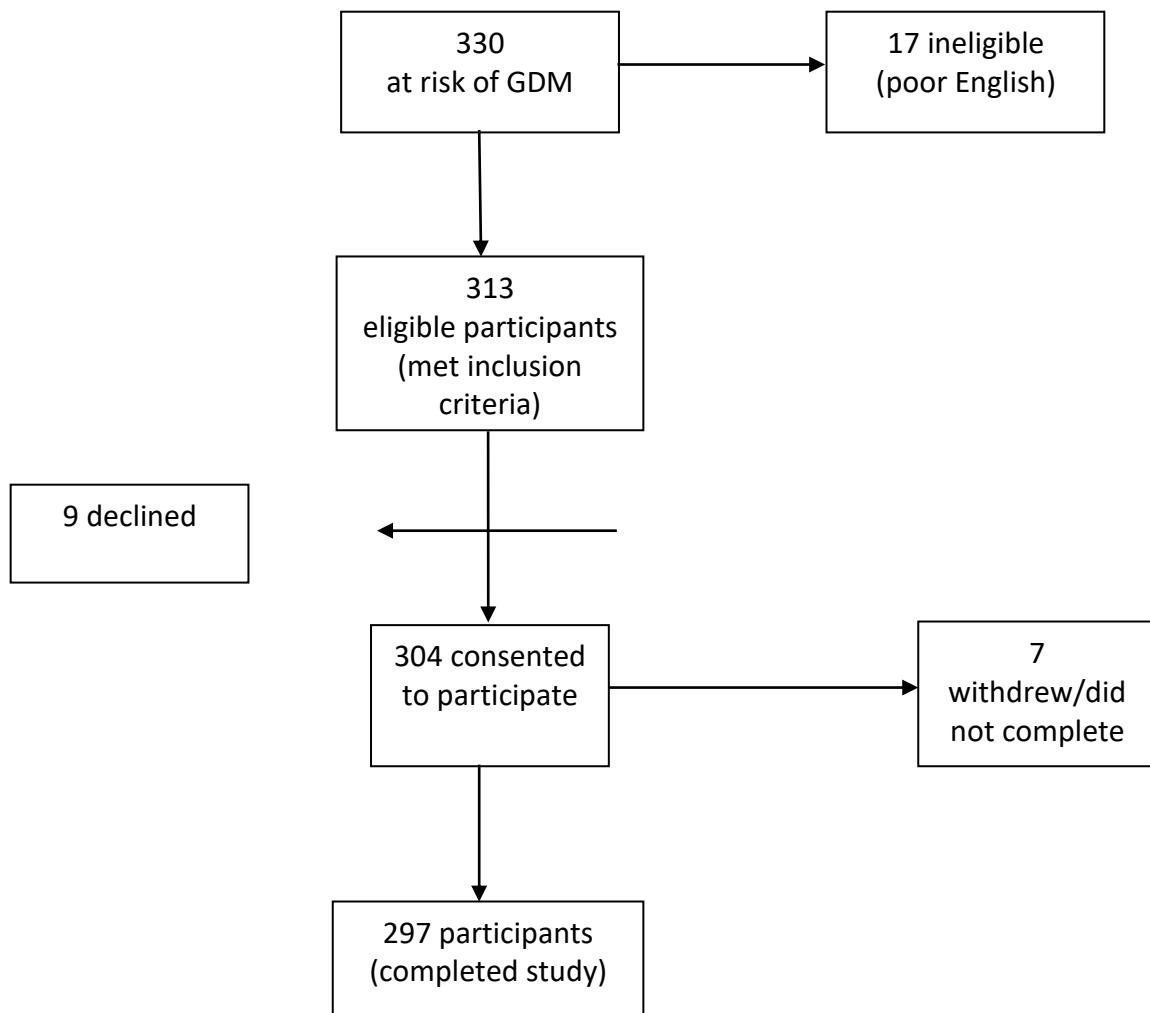


Figure 3.1 Flow diagram of study participants

\* risk factors in ATLANTIC DIP screening for GDM (table 1.8)

Characteristics*	Number
Aged 30 years or older	266
BMI $\geq 25\text{kg/m}^2$	122
PCOS	30
Previous GDM	9
Family history of diabetes	79
Ethnic subgroups	16
Polyhydramnios in current pregnancy	2
Macrosomia in current pregnancy	1

Table 3.1 Risk factors for GDM (ATLANTIC DIP clinical screening tool)

## Results

### Baseline Demographic Data of 297 Pregnant women at increased risk of GDM

	N (%)
Age, mean, range (years)	33.9 (19-49)
Ethnicity No. (%) n= 296	
Both parents born in Ireland	220 (74.3)
One parent born in Ireland and the other another EU state	14 (4.7)
Both parents born in another EU member state	37 (12.5)
One parent born in Ireland and the other born outside of EU	5 (1.7)
Both parents born outside of EU	20 (6.8)
Marital status No. (%) n = 296	
Married	218 (73.6)
Not married	72 (24.3)
Separated/Divorced	6 (2.0)
Smoking status No. (%) n= 296	
Never smoked	183 (61.8)
Stopped before pregnancy	72 (24.3)
Stopped when pregnant	29 (9.8)
Current smoker	12 (4.1)
Alcohol in past 30 days No. ( %) n= 294	
Yes	32 (10.9)
No	260 (87.5)
Don't know	2 (0.7)
Employment status No. (%) n= 293	
Full-time employment	192 (64.5)
Part-time employment	36 (12.3)
Self-employed	13 (4.4)
Unemployed	17 (5.8)
Full-time homemaker or carer	31 (10.6)
Student or on work experience	5 (1.7)
Education attainment No. (%) n= 293	
Pre-primary education	1 (0.3)
Primary education	3 (1.0)
Lower secondary	4 (1.4)
Upper secondary	18 (6.1)
Post-secondary/non-third level	40 (13.6)
Third level	89 (30.4)
Third level/postgrad Diploma/Master/PhD	138 (47.5)
Exercise No. (%) n=291	
Almost every day	41 (14.1)
A few times a week	104 (35.7)
A few times a month	90 (30.9)
Not at all	33 (11.3)
Not able to exercise	23 (7.9)
Health Insurance No. (%) n= 296	
Public	61 (20.6)
Private	133 (44.9)
Public & Private	37 (12.5)

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None	65 (22.0)
Self-rated Health No. (%) n= 293	
Very good	128 (43.7)
Good	148 (50.5)
Fair	16 (5.5)
Poor	1 (0.3)
Social status (self-rated) No. (%) n=290	
Very high	9 (3.1)
High	41 (14.1)
Upper middle	93 (32.1)
Middle	80 (27.6)
Lower middle	56 (19.3)
Low	6 (2.1)
Very low	5 (1.7)
Monthly Income (net)	
Less than €800	11 (3.8)
€800 to under €1,350	18 (6.2)
€1,350 to under €1,850	25 (8.6)
€1,850 to under €2,400	28 (9.6)
€2,400 to under €2,950	30 (10.3)
€2,950 to under €3,600	30 (10.3)
€3,600 to under €4,400	49 (16.8)
€4,400 to under €5,250	44 (15.1)
€5,250 to under €6,450	41 (14.1)
€6,450 or more	14 (4.8)
Self-perceived Health Literacy	
High	45 (15.4)
Above average	74 (25.3)
Adequate	168 (57.3)
Low/inadequate	6 (2.0)

Table 3.2 Socio-demographic Characteristics of participants

Table 3.2 summarises the socio-demographic characteristics of participants. Mean age of participants was 33.9 years, with a range from 19 to 49 years. Two hundred and eighteen participants (73.6%) were married, 72 participants (24.3%) were not married or were single and 6 participants (2.0%) were separated or divorced. Two hundred and twenty participants (74.3%) indicated that both their parents were born in Ireland; 14 participants (4.7%) indicated that one parent was born in Ireland and the other in another European Union (EU) member state; 37 participants (12.5%) indicated that both parents were born in another EU member state; 5 participants (1.7%) indicated that one parent was born in Ireland and the other was born outside of the EU and the remaining 20 participants (6.8%) indicated that both parents were born outside of the

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EU. Ethnicity data was available on 296 participants. One hundred and eighty three participants (61.8%) indicated they had never smoked, 72 (24.3%) stopped smoking before the current pregnancy, 29 (9.8%) stopped smoking when the current pregnancy was confirmed and 12 (4.1%) were current smokers. The majority of participants (88.4%) did not have an alcoholic drink in the preceding 30 days. Data on alcohol consumption in the past 30 days was available on 294 participants.

Third level education was successfully completed by 227 participants (76.5%). A further 40 participants (13.6%) successfully completed a post-secondary/non-third level education course and a further 18 participants (6.1%) completed upper secondary education. Four participants (1.4%) finished formal education at the lower secondary level, 3 participants (1.0%) at the end of primary education and 1 participant (0.3%) did not attend primary education. Education data was available on 293 participants.

Employment status of participants, showing that 192 (65.5%) were in fulltime employment, 36 (12.3%) were in part-time employment, 13 (4.4%) were self-employed, 17 (5.8%) were unemployed, 31 (10.6%) were either fulltime homemaker or carer and 5 (1.7%) were students. Employment data was available on 293 participants.

With regard to exercise 104 (35.7%) participants exercised a few times a week, while 41 (14.1%) exercised almost every day. The remaining 146 participants (50.2%) exercised only a few times a month or not at all. Data on exercise was available on 291 participants. One hundred and twenty eight participants (43.7%) rated their health as very good, 148 (50.5%) as good, 16 (5.5%) as fair and only 1 participant (0.3%) rated her health as poor. Self-rated health was available on 293 participants.

Participants were given an explanation of health literacy as “Health literacy refers to your level of understanding of information about your own health, general health information and information about the health service” and asked to indicate their level of health literacy (appendix D). One hundred and sixty eight participants (57.3%) rated their health literacy

## Results

as adequate, 74 (25.3%) as above average, 45 (15.4%) as high. Only 6 participants (2.0%) rated their health literacy as low or inadequate.

One hundred and thirty three participants (44.9%) had private health insurance and a further 37 (12.5%) participants had public and private health insurance. The remaining 42.5% had either public health insurance (61 participants) or no health insurance (65 participants). Health insurance data was available on 296 participants.

Self-perceived social status was measured on a scale from 1 to 10. It was explained to participants that step '1' on this scale corresponds to "the lowest level in the society" and step '10' corresponds to the highest level in the society. Participants were then asked to pick which step between 1 and 10 where they would place themselves. This self-assessed social status equates with a subjective indicator of socio-economic status. Fifty participants (17.2%) had a social status position in the high or very high position, 93 participants (32.1%) had a self-rated social status in the upper middle position, 80 participants (27.6%) had a middle position self-assessed social status, 56 participants (19.3%) had a lower middle position and 11 participants (3.8%) had a self-assessed social status in the low or very low position. The median self-assessed social status was 6. Self-rated social status was available on 290 participants.

Finally household income results revealed that eleven participants (3.8%) had a net income less than €800, 18 participants (6.2%) had a net household income from €800 to under €1,350, 25 participants (8.6%) had a net household income from €1,350 to under €1,850, 28 participants (9.6%) had a net household income from €1,850 to under €2,400, 30 participants (10.3%) had a net household income from €2,400 to under €2,950 and a further 30 participants (10.3%) from €2,950 to under €3, 600. In the income ranges €3,600 to under €4,400 , €4,400 to under €5,250 and €5,250 to under €6,450 there were 49 participants (16.8%), 44 participant (15.1%) and 41 participants (14.1%) respectively. The remaining 14 participants (5.8%) indicated that they had a net household income of €6,450 or more.

### 3.2 Health Literacy results

*Functional Health Literacy: results of Newest Vital Sign (NVS)*

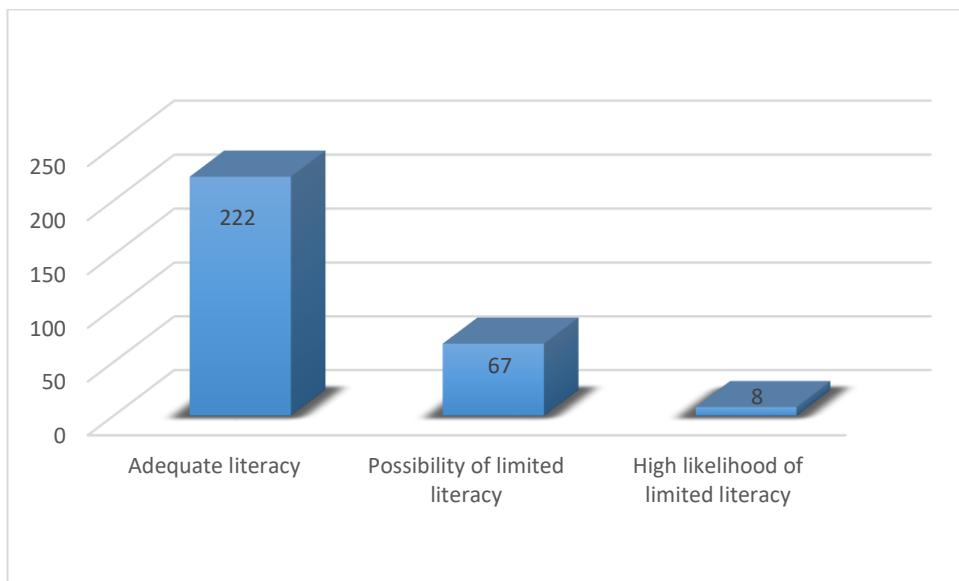


Figure 3.2 Newest Vital Sign (U.K.) results

Median Newest Vital Sign (NVS) score was 5 with an interquartile range of 3 to 6. Figure 3.2 demonstrates that 8 participants (2.7%) had a high likelihood of limited health literacy, 67 participants (22.6%) a possibility of limited health literacy and 222 (74.7%) participants had adequate health literacy. Combining the 'possibility of limited health literacy' group with the 'high likelihood of limited health literacy' group gives a total of 75 participants (25.3%) who had limited health literacy. This equates to 1 in 4 participants having limited functional health literacy.

Test for normality was conducted and revealed a non-normality distribution, with a median of 5 and interquartile range of 3. The histogram of the NVS data confirmed the skewedness of the distribution of scores in the NVS, with scores of 4-6 more frequent than scores of 1-3 (figure 3.3).

## Results

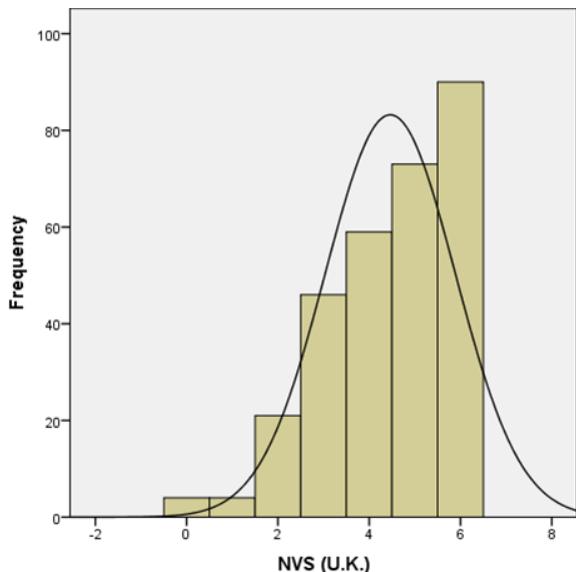


Figure 3.3 Distribution of NVS scores

### *EU HLS Indices Results*

Data of all 4 HLS indices was tested for normality by exploring mean, median, 5% trimmed mean, skewedness score and creation of histograms. Figure 3.4 displays the histograms for all 4 indices, which depicts normal distribution for these indices.

## Results

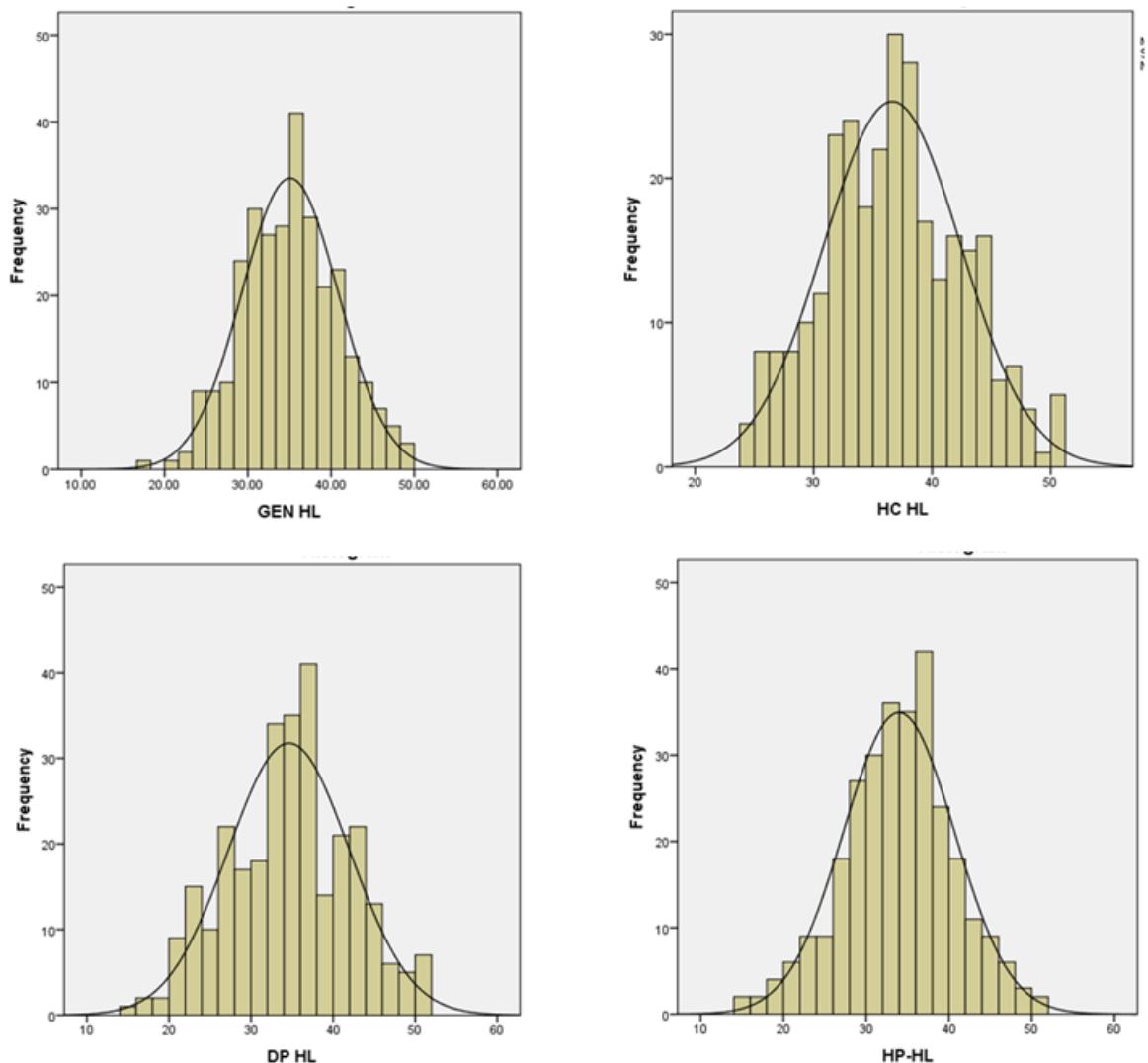


Figure 3.4 Distribution of HLS health literacy indices.

### *EU HLS Indices Results*

As detailed in the methods section, chapter 8, four indices of health literacy (HL), were calculated from the EU HLS questionnaire (EU HLS-Q), namely a General health literacy (GEN HL) index, a Health Care health literacy (HC HL) index, a Disease Prevention health literacy (DP HL) index and a Health Promotion health literacy (HP HL) Index. Data of the 4 indices was tested for normality by exploring mean, median, 5% trimmed mean, skewedness score and creation of histograms

Calculations and conversion of data to a standardized metric with each index having a value between 0 and 50 to facilitate comparisons are

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detailed in the methods section. Table 3.3 depicts summary results of the 4 health literacy indices of the EU HLS –Q.

<b>Health Literacy Indices</b>			
<b>Index</b>	<b>Mean</b>	<b>SD</b>	<b>Number*</b>
GEN HL	35.07	5.8	293
HC-HL	36.63	5.7	294
DP-HL	34.61	7.4	294
HP-HL	33.96	6.7	293

Table 3.3 EU HLS-Q indices results

GEN-HL general health literacy index. HC-HL health care health literacy.

DP-HL disease prevention health literacy. HP-HL health promotion health literacy.

\*Number represents the number of participants' scores in the index calculation.

The mean values for indices show that participants scored higher in the health care index than in the disease prevention and health promotion indices and, lowest in the health promotion index. Score intervals for the 4 categories of the metric for all indices were defined by the authors of the EU HLS as follows:

Inadequate: 0-25

Problematic: >25 to 33

Sufficient: >33 to 42

Excellent: >42 to 50

The mean values for all 4 indices, therefore, fall into the sufficient category.

Results of the GEN HL index (calculated from all 47 items in the scale) reveal that 4% had inadequate and 34% problematic health literacy; this means that 38% or approximately 4 in 10 had inadequate health literacy (table 3.4). Forty nine percent had sufficient health literacy and 13% excellent health literacy. Table 3.4 shows the number of participants and

## Results

percentages in each of the 4 indices. This confirms that more participants fell into the sufficient or excellent categories in the health care index (HC-HL) than in the disease prevention or health

Health Literacy Indices				
Category	GEN-HL No. (%)	HC-HL No. (%)	DP-HL No. (%)	HP-HL No. (%)
Inadequate	13 (4%)	6 (2.04%)	31 (10.54%)	31 (10.58%)
Problematic	100 (34%)	66 (22.45%)	78 (26.53%)	97 (33.11%)
Sufficient	142 (49%)	166 (56.46%)	132 (44.9%)	134 (45.73%)
Excellent	38 (13%)	56 (19.05%)	53 (18.03%)	31 (10.58%)

Table 3.4 Frequencies in each category in the 4 indices of the EU HLS-Q

promotion health literacy indices. The health promotion index (HP-HL) had a lower percentage of participants who scored sufficient or excellent scores (56.31%) compared with the health care index (75.51%) and the disease prevention index (62.93%).

### *Functional Health Literacy and Health Literacy Index (HL GEN index)*

Calculation of Spearman's rho was conducted to explore the relationship between Newest Vital Sign measure of functional health literacy and the general health literacy index scores. Rho was -0.04 which indicates almost no correlation between these 2 measures of health literacy in our sample.

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### *EU HLS-Q items' Results*

Tables 3.5, 3.6 and 3.7 list the items in the 3 sub-indices of the HLS and provide the numbers and percentages of participants, who selected each of the 5 possible answers, i.e. very difficult, fairly difficult, fairly easy, very easy or don't know, in each item. Participants were given the answer options and asked each item starting with the phrase "On a scale from very easy to very difficult, how easy would you say it is to...?"

## Results

Health Care Health Literacy Items	1 very difficult	2 fairly difficult	3 fairly easy	4 very easy	5 don't know
<b>Q 1.1 find information about symptoms of illnesses that concern you?</b>	3 (1.0)	4 (1.3)	129 (43.4)	161 (54.2)	0 (0.0)
<b>Q1.2 find information on treatments of illnesses that concern you?</b>	2 (0.7)	27 (9.1)	170 (57.2)	97 (32.7)	1 (0.3)
<b>Q.1.3 find out what to do in case of a medical emergency?</b>	0 (0.0)	36 (12.1)	159 (53.5)	102 (34.3)	0 (0.0)
<b>Q.1.4 find out where to get professional help when you are ill?</b>	1 (0.3)	9 (3.0)	128 (43.1)	159 (53.5)	0 (0.0)
<b>Q.1.5 understand what your doctor says to you?</b>	0 (0.0)	26 (8.8)	161 (54.4)	109 (36.8)	0 (0.0)
<b>Q.1.6 understand the leaflets that come with your medicine?</b>	4 (1.4)	55 (18.6)	141 (47.6)	96 (32.4)	0 (0.0)
<b>Q.1.7 understand what to do in a medical emergency?</b>	4 (1.4)	69 (23.3)	156 (52.7)	67 (22.6)	0 (0.0)
<b>Q1.8 understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?</b>	0 (0.0)	5 (1.7)	104 (35.1)	187 (63.2)	0 (0.0)
<b>Q1.9 judge how information from your doctor applies to you?</b>	0 (0.0)	12 (4.1)	157 (53.0)	127 (42.9)	0 (0.0)
<b>Q1.10 judge the advantages and disadvantages of different treatment options?</b>	10 (3.4)	98 (33.1)	152 (51.4)	34 (11.5)	2 (0.6)
<b>Q1.11 judge when you may need to get a second opinion from another doctor?</b>	21 (7.1)	141 (47.6)	96 (32.4)	34 (11.5)	4 (1.4)
<b>Q1.12 judge if information about illness in the media is reliable?</b>	45 (15.3)	152 (51.5)	78 (26.4)	18 (6.1)	2 (0.7)
<b>Q1.13 use information the doctor gives to make decisions about your illness?</b>	2 (0.7)	34 (11.6)	190 (64.6)	68 (23.1)	0 (0.0)
<b>Q1.14 follow the instruction on medication?</b>	0 (0.0)	7 (2.4)	114 (38.6)	174 (59.0)	0 (0.0)
<b>Q1.15 call an ambulance in an emergency?</b>	2 (0.7)	18 (6.1)	80 (27.2)	192 (65.3)	2 (0.7)
<b>Q1.16 follow instructions from your doctor or pharmacist?</b>	0 (0.0)	3 (1.0)	104 (35.3)	188 (63.7)	0 (0.0)

Table 3.5 Frequency table of items in the Health care HL index. Values are number (percentage).

### *Health care Index findings*

Table 3.5 lists the first 16 items of the 47 items of the HLS, which are included in the calculation of the health care index. From this we can identify a number of items that a high percentage of participants found difficult, either fairly difficult or very difficult. These results reveal that 36.5% of participants found it difficult to judge the advantages and

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disadvantages of different treatment options, 54.7% of participants found it difficult to judge when they may need to get a second opinion from another doctor and 66.8% of participants found it difficult to judge if information about illness in the media is reliable. Furthermore one in five (20%) found it difficult understanding the leaflets that come with medicines. Items where the participant had to find information or follow instructions, such as follow instructions from your doctor or pharmacist, or find information such as find information on illnesses were easy for the majority of participants.

### *Disease Prevention Index findings*

Table 3.6 lists items 17 to 31 of the HLS, which are used in the calculation of the disease prevention index. Notable findings from this table are items 26, 28, 29, 30 and 31. A high number of participants, namely 42.3% found it difficult to judge which vaccinations they might need; similarly 42.4% found it difficult to decide if they should have the flu vaccination. Judging how reliable information in the media is on health risks was difficult for 58.5% of participants and deciding how to protect oneself from illness based on information in the media was difficult for 49.7% of participants. Deciding how to protect oneself from illness based on advice from family and friends was difficult for almost half of the participants (45.9%). Finally approximately 1 in 5 found it difficult to judge when they need to go to a doctor for a check-up (19.4%); to judge which health screenings they might need (22.7%) and to understand why they need vaccinations (22.1%).

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Disease Prevention Health Literacy Items	1 very difficult	2 fairly difficult	3 fairly easy	4 very easy	5 don't know
<b>Q1.17 find information about how to manage unhealthy behaviour such as smoking, low physical activity and drinking too much?</b>	2 (0.7)	6 (2.0)	86 (29.2)	200 (67.8)	1 (0.3)
<b>Q1.18 find information on how to manage mental health problems like stress or depression?</b>	7 (2.4)	76 (25.8)	140 (47.5)	71 (24.1)	1 (0.3)
<b>Q1.19 find information about vaccinations and health screenings that you should have?</b>	6 (2.0)	48 (16.3)	149 (50.5)	92 (31.2)	0 (0.0)
<b>Q1.20 find information on how to prevent or manage conditions like being overweight, high blood pressure or high cholesterol?</b>	3 (1.0)	20 (6.8)	155 (52.7)	117 (39.7)	0 (0.0)
<b>Q1.21 understand health warnings about behaviour such as smoking, low physical activity and drinking too much?</b>	1 (0.3)	7 (2.4)	79 (26.9)	207 (70.4)	0 (0.0)
<b>Q1.22 understand why you need vaccinations?</b>	5 (1.7)	60 (20.4)	110 (37.4)	119 (40.5)	0 (0.0)
<b>Q1.23 understand why you need health screenings?</b>	1 (0.3)	13 (4.4)	109 (37.1)	171 (58.2)	0 (0.0)
<b>Q1.24 judge how reliable health warnings are, such as smoking, low physical activity and drinking too much?</b>	0 (0.0)	18 (6.1)	96 (32.7)	180 (61.2)	0 (0.0)
<b>Q1.25 judge when you need to go to a doctor for a check-up?</b>	5 (1.7)	52 (17.7)	127 (43.3)	109 (37.2)	0 (0.0)
<b>Q1.26 judge which vaccinations you may need?</b>	14 (4.8)	110 (37.5)	104 (35.5)	63 (21.5)	2 (0.7)
<b>Q1.27 judge which health screenings you may need?</b>	6 (2.0)	61 (20.7)	137 (46.6)	90 (30.6)	0 (0.0)
<b>Q1.28 judge if the information on health risks in the media is reliable?</b>	27 (9.2)	145 (49.3)	100 (34.0)	22 (7.5)	0 (0.0)
<b>Q1.29 decide if you should have the flu vaccination?</b>	29 (9.9)	95 (32.5)	83 (28.4)	85 (29.1)	0 (0.0)
<b>Q1.30 decide how you can protect yourself from illness based on advice from family and friends?</b>	26 (8.8)	109 (37.1)	108 (36.7)	49 (16.7)	2 (0.7)
<b>Q1.31 decide how you can protect yourself from illness based on information in the media?</b>	32 (10.9)	114 (38.8)	122 (41.5)	25 (8.5)	1 (0.3)

Table 3.6 Frequency table for items in the Disease Prevention HL index. Values are number (percentage).

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Health Promotion Health Literacy Items	1 very difficult	2 fairly difficult	3 fairly easy	4 very easy	5 don't know
<b>Q1.32 find information on healthy activities such as exercise, healthy food and nutrition?</b>	3 (1.0)	13 (4.4)	93 (31.6)	185 (62.9)	0 (0.0)
<b>Q1.33 find out about activities that are good for you mental well-being?</b>	3 (1.0)	24 (8.2)	125 (42.5)	142 (48.3)	0 (0.0)
<b>Q1.34 find information on how your neighbourhood could be more health friendly?</b>	40 (13.6)	133 (45.2)	90 (30.6)	28 (9.5)	3 (1.0)
<b>Q1.35 find out about political changes that may affect health?</b>	49 (16.7)	142 (48.3)	92 (31.3)	11 (3.7)	0 (0.0)
<b>Q1.36 find out about efforts that promote your health at work?</b>	17 (5.8)	67 (22.9)	147 (50.2)	51 (11.7)	11 (3.8)
<b>Q1.37 understand advice on health from family and friends?</b>	10 (3.4)	69 (23.5)	154 (52.4)	61 (20.7)	0 (0.0)
<b>Q1.38 understand information on food packaging?</b>	25 (8.5)	80 (27.2)	136 (46.3)	52 (17.7)	1 (0.3)
<b>Q1.39 understand information in the media on how to get healthier?</b>	3 (1.0)	44 (15.0)	170 (57.8)	77 (26.2)	0 (0.0)
<b>Q1.40 understand information on how to keep your mind healthy?</b>	4 (1.4)	51 (17.4)	168 (57.3)	70 (23.9)	0 (0.0)
<b>Q1.41 judge how where you live affects your health and well-being?</b>	22 (7.5)	69 (23.5)	137 (46.6)	66 (22.4)	0 (0.0)
<b>Q1.42 judge how your housing conditions help you to stay healthy?</b>	22 (7.5)	32 (10.9)	142 (48.3)	98 (33.3)	0 (0.0)
<b>Q1.43 judge which everyday behaviour is related to your health?</b>	2 (0.7)	10 (3.4)	118 (40.1)	164 (55.8)	0 (0.0)
<b>Q1.44 make decisions to improve your health?</b>	5 (1.7)	42 (14.3)	130 (44.4)	116 (39.6)	0 (0.0)
<b>Q1.45 join a sports club or exercise class if you want to?</b>	9 (3.1)	28 (9.6)	96 (32.8)	160 (54.6)	0 (0.0)
<b>Q1.46 influence your living conditions that affect your health and well-being?</b>	5 (1.7)	39 (13.3)	119 (40.6)	130 (44.4)	0 (0.0)
<b>Q1.47 take part in activities that improve health and well-being in your community?</b>	10 (3.4)	49 (16.7)	120 (41.0)	114 (38.9)	0 (0.0)

Table 3.7 Frequency table for items in the Health Promotion HL index. Values are number (percentage).

*Health promotion Index findings*

Table 3.7 lists items 32 to 47 of the HLS, which are used in the calculation of the health promotion index. Items 34, 35, 36, 38 and 41 are notable in that a significant percentage of participants had difficulty with these health promotion-related tasks. For example 58.8% found it difficult to find information on how their neighbourhood could be more health friendly and 65% found it difficult to find out about political changes that may affect health. A high number of participants (35.7%) had difficulty understanding information on food packaging; 31% also found it difficult to judge how where they lived affected their health and well-being. Finding out about efforts to promote health at work was difficult for 28.7% of participants and 20.1% of participants found it difficult to take part in activities that improve health and well-being in their community.

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### 3.3 Pregnancy-related factors and adverse pregnancy outcomes

Five of the participants moved away from the region and did not continue to attend the obstetrical department in our hospital. A further 5 were twin pregnancies and were excluded from the analysis of antenatal complications, delivery and pregnancy outcomes.

#### *OGTT results*

The 75g OGTT was conducted according to the protocol described in the methods section. GDM was diagnosed based on the AIDPSG diagnostic criteria. Table 3.8 provides the mean and standard deviations for fasting,

GTT results		
Time	Glucose mmol/L Mean (SD)	Number meeting or exceeding threshold*
Fasting	4.40 (0.42)	17
1-hour	7.17 (5.65)	16
2-hour	5.14 (1.31)	5
GDM (one or more thresholds met or exceeded)		30

Table 3.8 Glucose tolerance test results SD is standard deviation

\*Thresholds for GDM according to the AIDPSG diagnostic criteria.

1-hour and 2-hour plasma glucose levels. A total of 30 participants were diagnosed with GDM, representing 10.3% of participants. GTT results are on 292 participants who completed the OGTT. Ten of those diagnosed with GDM (33.3%) required treatment with insulin.

Summary statistics of pregnancy characteristics and outcomes are shown in table 3.9. There was a family history of diabetes (first and/or second

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degree relatives) in 84 participants (29.47%). Nine participants (3.19%) had an obstetrical history of GDM. The mean gravida of participants was 2.54 and mean parity was 1.03 with a standard deviation of 1.59. Pre-pregnancy folic acid treatment was taken by 181 (64.18%) of participants. A normal BMI,

Characteristics	Mean +/- SD Number (%)	Characteristics	Mean +/- SD Number (%)
Parity	1.03 +/- 1.14	Adverse outcomes	
Gravida	2.54 +/- 1.59	Gestational hypertension	17 (6.0 %)
Booking BMI, kg/m <sup>2</sup>	25.96 +/- 5.06	Pre-eclampsia	4 (1.4%)
Booking BMI category		Polyhydramnios	2 (0.7%)
Normal	149 (53.8%)	Antepartum haemorrhage	4 (1.4%)
Overweight	81 (29.2%)	Postpartum haemorrhage	40 (14.1%)
Obese	47 (17.0%)	GDM*	30 (10.3%)
Pre-pregnancy folic acid	181 (64.2%)	Caesarean section delivery	101 (35.4%)
Family history of DM	84 (29.5%)	Assisted vaginal delivery	47 (16.5%)
History of GDM	9 (3.2%)	Prematurity	16 (5.2%)
SBP	121.68 +/- 10.92	Stillbirths	1 (0.3%)
DBP	68.91 +/- 9.67	Macrosomia	46 (16.1%)
Breast feed (first feed)	190 (65.6%)	LGA	31 (10.9%)
APGAR at 1 minute	8.73 +/- 0.82	SGA	23 (8.1%)
APGAR at 5 minutes	9.38 +/- 0.56	Shoulder dystocia	0 (0.0%)
		Malformations (cystic hygroma)	1 (0.3%)
		Neonatal hypoglycemia	0 (0.0%)
		NICU admission	12 (4.2%)

Table 3.9 Pregnancy characteristics and outcomes \*see table 3.8

at the time of first antenatal visit to the department, was recorded for 149 participants (53.8%), while 81 participants (29.2%) were overweight and 47 participants (17%) were obese. Caesarean section delivery was conducted in 101 cases (35.4%). Of these 101 cases 50 were emergency caesarean sections. After GDM, gestational hypertension was the next most frequent antenatal complication, occurring in 17 participants (6%), followed by pre-eclampsia in 4 participants (1.4%) and polyhydramnios in 2 cases (0.7%). The incidence of stillbirth was low, occurring in 1 participant (0.3%). There

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were 46 neonates (16.1%) with macrosomia; LGA and SGA were diagnosed in 31 (10.9%) and 23 (8.1%) neonates respectively. There were no cases of neonatal hypoglycaemia. Twelve neonates were admitted to the neonatal intensive care unit (NICU). Eight were admitted with respiratory distress, 2 with infections, 1 had feeding difficulty and 1 was admitted for prematurity.

### **3.4 Health literacy and socio-demographic factors**

#### *Functional Health Literacy*

Functional health literacy was converted to a dichotomous variable by high likelihood of limited literacy and possibility of limited literacy to form a limited health literacy category. Table 3.10 details the socio-demographic characteristics by functional health literacy status, as measured by the NVS (U.K.). When numbers were sufficient in each crosstab cell (minimum of 5), Pearson Chi-Square p value is provided. P values < 0.05 were interpreted as statistically significant differences between the groups.

## Results

	All	Limited health literacy	Adequate health literacy	P Value
All	297 (100)	75 (25.3)	222 (74.7)	
Education				
Lower secondary or less	8 (2.7)	5 (6.8)	3 (1.4)	
Upper secondary or post-secondary	58 (19.8)	22 (30.1)	36 (16.4)	
Third level	227 (77.5)	46 (63.0)	181 (82.3)	
Employment status				
Full-time employment	192 (65.3)	39 (52.7)	153 (69.5)	
Part-time employment	36 (12.2)	12 (16.2)	24 (10.9)	
Self-employed	13 (4.4)	1 (1.4)	12 (5.5)	
Unemployed	17 (5.8)	10 (13.5)	7 (3.2)	
Full-time homemaker or carer	31 (10.5)	8 (10.8)	23 (10.5)	
Student or on work experience	5 (1.7)	4 (5.4)	1 (0.5)	
Parental Ethnic Background				
Both parents born in Ireland	220 (74.3)	43 (57.3)	177 (80.1)	< 0.001
One parent born in Ireland	19 (6.4)	5 (6.7)	14 (6.3)	
Both parents born in another EU member state	37 (12.5)	16 (21.3)	21 (9.5)	
Both parents born outside of EU	20 (6.8)	11 (14.7)	9 (4.1)	
Exercise				
A few times a week or more	145 (49.8)	45 (61.6)	100 (45.9)	
A few times a month or less	122 (41.9)	25 (34.2)	97 (44.5)	
Not able to exercise	24 (8.2)	3 (4.1)	21 (9.6)	
Smoking				
Never smoked	183 (61.8)	45 (60.0)	138 (62.4)	0.02
Former smoker	101 (34.1)	23 (30.7)	78 (35.3)	
Current smoker	12 (4.1)	7 (9.3)	5 (2.3)	
BMI				
Normal	147 (53.5)	35 (52.2)	112 (53.8)	0.73
Overweight	81 (29.5)	22 (32.8)	59 (28.4)	
Obese	47 (17.0)	10 (14.9)	37 (17.8)	
Health Insurance				
Private	170 (57.4)	25 (33.3)	145 (65.6)	<0.001
Public	61 (20.6)	26 (34.7)	35 (15.8)	
None	65 (22.0)	24 (32.0)	41 (18.6)	
Self-rated health status				
Very good	128 (43.7)	33 (44.6)	95 (43.4)	
Good	148 (50.5)	38 (51.4)	110 (50.2)	
Fair or Poor	17 (5.8)	3 (4.1)	14 (6.4)	
Social status (self-rated)				
High	49 (16.9)	10 (14.1)	39 (17.8)	0.18
Middle	174 (60.0)	39 (54.9)	135 (61.6)	
Low	67 (23.1)	22 (31.0)	45 (20.5)	
Income (monthly)				
Level 1 < €1,350	29 (10.0)	18 (25.4)	11 (5.0)	<0.001
Level 2 €1,350 to < €3,600	113 (39.0)	35 (49.3)	78 (35.6)	
Level 3 €3,600 to < €5,250	93 (32.0)	13 (18.3)	80 (36.5)	
Level 4 >= €5,250	55 (19.0)	5 (7.0)	50 (22.8)	

Table 3.10 Demographic characteristics by functional health literacy status

Values are numbers and percentages in brackets

## Results

### *Functional Health Literacy and Education*

More than three quarters of participants (77.5%) had completed third level education. As numbers were less than 5 in some cells it was not possible to test for statistically significant differences in the frequencies of limited and adequate functional health literacy across the educational groups. The data, however, shows a higher percentage of participants with third level education in the adequate functional health literacy group compared with the limited functional health literacy group, 82.3% versus 63% respectively.

### *Functional Health Literacy and Employment status*

The majority were in fulltime employment (65.3%) and a small percentage were unemployed (5.8%). As numbers were less than 5 in some cells it was not possible to test for statistically significant between group differences in functional health literacy. The data does show a lower percentage of the limited functional health literacy group in fulltime employment (52.7%) compared with those with adequate functional health literacy who are in fulltime employment (69.5%). In the group with limited functional health literacy 13.5% are unemployed but the unemployed make up only 3.2% of the group with adequate functional health literacy.

### *Functional Health Literacy and Ethnicity*

Differences in the frequencies of limited and adequate functional health literacy were statistically significant across the ethnic groups, with higher levels of limited functional health literacy when one or both parents were born outside of the EU than and lower functional health literacy levels when both parents were born in Ireland. For example while 12.5% of all participants had one parent born outside of the EU, 21.3% of those with limited health literacy were from this ethnic group. Conversely 74.3% of participants had parents who were both born in Ireland but in the limited functional health literacy group this group made up only 57.3%. Differences in functional health literacy and ethnic origins were significant at the 0.001 level.

## Results

### *Functional Health Literacy and Exercise*

As numbers were less than 5 in some cells it was not possible to test for statistically significant differences in the frequencies of limited and adequate functional health literacy across exercise groups. The data does show that approximately half (49.8%) exercised daily or a few times a week, while the other half of the whole group exercised infrequently or not at all. The data also show that a higher percentage of those with limited functional health literacy exercised at least a few times a week compared with those with adequate functional health literacy, 61.6% versus 45.9% respectively.

### *Functional Health Literacy and Smoking*

Overall 4.1% of participants were current smokers. In those with limited functional health literacy this rose to 9.3% and only 2.3% of those with adequate functional health literacy were current smokers. Differences in functional health literacy and smoking status were statistically significant at the 0.02 level.

### *Functional Health Literacy and BMI*

In my study sample 53.5% had a normal BMI, 29.5% were overweight and 17% were obese. There were no statistically significant differences in health literacy across the 3 BMI groups.

### *Functional Health Literacy and Health Insurance*

While 22% of all participants had no health insurance, this was higher in those with limited functional health literacy (32%) and lower in those with adequate health literacy (18.6%). Differences in functional health literacy and health insurance status were statistically significant at the <0.001 level.

## Results

### *Functional Health Literacy and Self-rated Health status*

As numbers were less than 5 in some cells it was not possible to test for statistically significant differences in the frequencies of limited and adequate functional health literacy. Overall the majority of participants rated their health as very good or good (94.2%) and only 5.8% rated their health as fair or poor

### *Functional Health Literacy and self-assessed Social status*

Overall the majority of participants perceived their social status to be in the middle level (60%) with 16.9% in the high and 23.1% in the low (perceived) social status levels. A higher percentage of those with limited functional health literacy perceived their social status as low compared with those with adequate functional health literacy (20.5%). Differences were not statistically significant.

### *Functional Health Literacy and Income*

There was a statistically significant difference across the income groups with those on lower incomes having a higher percentage of participants with limited functional health literacy. For example, 25.4% of those with limited functional health literacy were in the lowest income group (monthly income less than €1,350) and only 7% with limited functional health literacy had incomes in the highest income group (greater or equal to €5,250). Also only 5% of those with adequate functional health literacy were in the lowest income group. Differences in functional health literacy levels across the income groups were statistically significant at the <0.001 level.

## Results

### *Determinants of Functional Health Literacy*

My next question was how much variance in functional health literacy can be explained by the following demographic variables: household income, parental ethnic background, education attainment, social status and self-rated health status? I was also interested in the magnitude of the prediction, in the case of those factors found to significantly predict functional health literacy. My selection of which variables to include in the regression analysis was based on findings in the literature on socio-demographic factors associations with health literacy. In the population studies in US, Canada, Australia and Europe the socio-demographic factors of education, age, employment, ethnicity, income, self-rated health status and self-perceived social status were found to be significantly associated with health literacy (4, 50, 52, 53). This influenced my selection of variables to include in my multiple regression analysis to determine predictors of health literacy. I did not include age as the age range was limited to women of child-bearing age. I also excluded employment as a high percentage of my sample were employed (88%) and there was a significant correlation between employment and income with a Pearson's correlation co-efficient of 0.40 ( $p= 0.01$ ). Including both employment status and income in the regression analysis would introduce multicollinearity in the model. Similarly there was likely to be a strong correlation between health insurance status and income in this age group and therefore in my sample. This can be explained by the eligibility criteria for public health insurance in Ireland (the General Medical Services card); in this age-group it is linked to income and the issue of multicollinearity would make it unsuitable to include both of these variables in the regression analysis. This lead to the selection of the variables of income (household), parental ethnic background, education, social status and self-rated health for inclusion in the regression analysis.

## Results

Table 3.11 summarises the multiple regression analysis of functional health literacy. The R square value is 0.203, which means that 20.3% of the variance in functional health literacy is explained by the factors included in the analysis. This value is statistically significant with a p value of 0.0005. Household income, parental ethnic background and education independently predicted functional health literacy at the level of significance  $p \leq .05$ . From the  $\beta$  values we can conclude that household income and education positively predicted functional health literacy. Parental ethnic background, across the categories of both parents born in Ireland, one parent born in Ireland, both parents born in another EU state and both parents born outside of the EU, negatively predicted functional health literacy. The strongest predictor was household income.

Demographic factors	
Household income	B= 0.267**
Parental ethnic background	B= -0.251**
Education	B= 0.128**
Social status	B= -0.017
Self-rated health	B= 0.042
R <sup>2</sup>	0.203*

Table 3.11 Predictors of functional health literacy

\*p= 0.0005; \*\*p = 0.008

## Results

### *General Health Literacy Index (GEN HL)*

	All	Limited HL	Adequate HL	P Value
All	293 (100)	113 (38.6)	180 (61.4)	
Education				
Lower secondary or less	7 (2.4)	3 (2.7)	4 (2.2)	
Upper secondary or post-secondary	57 (19.7)	22 (19.6)	35 (19.8)	
Third level	225 (77.8)	87 (77.7)	138 (78.0)	
Employment status				
Full-time employment	192 (61.9)	79 (70.5)	112 (62.9)	
Part-time employment	36 (11.6)	13 (11.6)	21 (11.8)	
Self-employed	13 (4.2)	3 (2.7)	9 (5.1)	
Unemployed	17 (5.5)	3 (2.7)	14 (7.9)	
Full-time homemaker or carer	31 (10.0)	14 (12.5)	17 (17.4)	
Student or on work experience	5 (1.6)	0 (0.0)	5 (2.8)	
Parental ethnic background				
Both parents born in Ireland	220 (74.3)	92 (82.1)	126 (70.4)	0.16
One parent born in Ireland	19 (6.4)	7 (3.9)	12 (6.7)	
Both parents born in another EU member state	37 (12.5)	9 (8.0)	27 (15.1)	
Both parents born outside of EU	20 (6.8)	5 (4.4)	14 (7.8)	
Exercise				
A few times a week or more	144 (50.2)	53 (47.3)	91 (52.0)	0.51
A few times a month or less	119 (41.5)	51 (45.5)	68 (38.9)	
Not able to exercise	24 (8.3)	8 (7.2)	16 (9.1)	
Smoking				
Never smoked	181 (62.0)	65 (57.5)	116 (64.8)	
Former smoker	99 (33.9)	40 (35.4)	59 (33.0)	
Current smoker	12 (4.1)	8 (7.1)	4 (2.2)	
BMI				
Normal	145 (53.5)	54 (51.9)	91 (54.5)	0.91
Overweight	80 (29.5)	32 (30.8)	48 (28.7)	
Obese	46 (17.0)	18 (17.3)	28 (16.8)	
Health Insurance				
Private	169 (57.9)	62 (54.9)	107 (59.8)	0.67
Public	60 (20.5)	24 (21.2)	36 (20.1)	
None	63 (21.6)	27 (23.9)	36 (20.1)	
Self-rated health status				
Very good	127 (43.9)	40 (35.7)	87 (49.2)	0.06
Good	147 (50.9)	64 (57.1)	83 (46.9)	
Fair or Poor	15 (5.2)	8 (7.1)	7 (4.0)	
Social status (self-rated)				
High	49 (17.0)	15 (13.5)	34 (19.1)	0.22
Middle	173 (59.9)	65 (58.5)	108 (60.7)	
Low	67 (23.2)	31 (27.9)	36 (20.2)	
Income (monthly)				
Level 1 < €1,350	29 (10.0)	15 (13.3)	14 (8.0)	0.22
Level 2 ≥ €1,350 to < €3,600	112 (38.8)	44 (38.9)	68 (38.6)	
Level 3 ≥ €3,600 to < €5,250	93 (32.2)	38 (33.6)	55 (31.3)	
Level 4 ≥ €5,250	55 (19.0)	16 (14.2)	39 (22.2)	

Table 3.12 Socio-demographic characteristics by general health literacy category

Values are number and percentages in brackets

## Results

Table 3.12 shows the results of overall health literacy, as measured with the general health literacy survey (GEN HL) index. Findings are described in the following paragraphs.

### *General Health Literacy and Education*

As numbers were less than 5 in some cells it was not possible to test for statistically significant differences in the frequencies of limited and health literacy across the educational groups. The data shows similar frequencies of limited and adequate health literacy in the educational groups.

### *General Health Literacy and Employment status*

As numbers were less than 5 in a number of cells it was not possible to test for statistically significant differences in health literacy between groups.

### *General Health Literacy and Ethnicity*

There was no statistically significant difference in health literacy across ethnicity groups. Participants, whose parents were born outside of the EU comprised a lower percentage of the limited health literacy group compared to the adequate health literacy group, 4.4% versus 7.8% respectively. Conversely participants, where both parents were born in Ireland comprised 82.1% of the limited health literacy group and only 70.4% of the adequate health literacy group.

### *General Health Literacy and Exercise*

There was no statistically significant difference in health literacy across exercise groups.

### *General Health Literacy and Smoking*

There were more current smokers in the limited health literacy group than in the adequate health literacy group, 7.1% and 2.2% respectively. As there was less than 5 in one of the cells chi square test for statistically significant difference across group was not tested.

## Results

### *General Health Literacy and BMI*

There was no statistically difference in health literacy across BMI categories.

### *General Health Literacy and Health Insurance*

There was a trend where a lower percentage of those with limited health literacy had private health insurance compared to those with adequate health literacy, 54.9% versus 59.8% respectively. Conversely a higher percentage of those with limited health literacy had no health insurance compared to those with adequate health literacy, 23.9% versus 20.1%. These differences did not reach statistical significance.

### *General Health Literacy and Self-rated Health status*

Frequencies in table 3.12 show that a lower percentage of those with limited health literacy rated their health as very good compared to those with adequate health literacy, 35.7% versus 49.2%. Conversely a higher percentage of those with limited health literacy rated their health as fair or poor compared to those with adequate health literacy, 7.1% versus 4.0% respectively. These differences did not reach statistical significance.

### *General Health Literacy and Social status*

A lower percentage of those with limited health literacy perceived their social status as high compared to those with adequate health literacy, 13.1% versus 19.1%. Conversely a higher percentage of those with limited health literacy perceived their social status as low compared to those with adequate health literacy, 27.9% versus 20.2%. These differences did not reach statistical significance.

### *General Health Literacy and Income*

These was no statistically significant difference in health literacy across the 4 income groups. However the data in table 3.12 shows that the percentage of those with an income of less than €1,350 was higher in the

## Results

limited health literacy group compared to the adequate literacy group, 13.3% versus 8% respectively. Conversely there was a lower percentage of those in the higher income level in the limited health literacy group compared to the adequate health literacy group, 14.25 versus 22.2%.

### *Determinants of Health Literacy (GEN-HL) Index*

My next question was how much variance in general health literacy can be explained by the following demographic variables: household income, parental ethnic background, education attainment, social status and self-rated status? I was also interested in the magnitude of the prediction, in the case of those factors found to significantly influence general health literacy.

Table 3.13 summarises the multiple regression analysis of the GEN-HL index. The R square value is 0.054, which means that 5.4% of the variance in this health literacy index is explained by the factors included in the analysis. This value is statistically significant with a p value of 0.009. Parental ethnic background and social status were positive predictors of health literacy. The other factors did not significantly impact on general health literacy.

Demographic factors	
Household income	B= 0.046
Parental ethnic background	B= 0.167**
Education	B= -0.167
Social status	B= 0.125**
Self-rated health	B= -0.061
R <sup>2</sup>	0.054*

Table 3.13 Predictors of general health literacy: multiple regression analysis

\*p=0.009; \*\*p= 0.005

## Results

### *Health Care Literacy Index (HC-HL)*

	All	Limited HL	Adequate HL	P Value
All	293 (100)	113 (38.6)	180 (61.4)	
Education				
Lower secondary or less	7 (2.4)	0 (0.0)	7 (2.4)	
Upper secondary or post-secondary	57 (19.7)	14 (19.7)	35 (19.7)	
Third level	225 (77.8)	57 (80.3)	138 (79.9)	
Employment status				
Full-time employment	192 (66.0)	50 (70.4)	142 (64.5)	
Part-time employment	34 (11.7)	7 (9.9)	27 (11.7)	
Self-employed	13 (4.5)	2 (2.8)	11 (5.0)	
Unemployed	16 (5.5)	2 (2.8)	14 (6.4)	
Full-time homemaker or carer	31 (10.7)	7 (12.7)	22 (10.0)	
Student or on work experience	5 (1.7)	1 (1.4)	4 (1.8)	
Parental ethnic background				
Both parents born in Ireland	219 (74.7)	61 (84.7)	158 (71.5)	
One parent born in Ireland	19 (6.5)	4 (5.6)	15 (6.8)	
Both parents born in another EU member state	36 (12.3)	5 (6.9)	31 (14.0)	
Both parents born outside of EU	19 (6.5)	2 (2.8)	17 (7.7)	
Exercise				
A few times a week or more	143 (49.7)	30 (42.3)	113 (52.1)	0.51
A few times a month or less	121 (42.0)	36 (50.7)	85 (39.2)	
Not able to exercise	24 (8.3)	5 (7.0)	19 (8.8)	
Smoking				
Never smoked	180 (61.4)	44 (61.1)	136 (61.5)	
Former smoker	101 (34.5)	24 (33.3)	77 (34.8)	
Current smoker	12 (4.1)	4 (5.6)	8 (3.6)	
BMI				
Normal	146 (53.5)	31 (48.5)	115 (55.3)	0.38
Overweight	79 (28.9)	23 (35.9)	56 (26.9)	
Obese	47 (17.2)	10 (15.6)	37 (17.8)	
Health Insurance				
Private	170 (58.0)	42 (58.3)	128 (57.9)	0.67
Public	59 (20.1)	16 (22.2)	43 (19.5)	
None	64 (21.8)	14 (19.4)	50 (22.6)	
Self-rated health status				
Very good	128 (44.1)	25 (35.2)	103 (47.0)	0.06
Good	146 (50.3)	40 (56.3)	106 (48.4)	
Fair or Poor	16 (5.5)	6 (8.5)	10 (4.6)	
Social status (self-rated)				
High	49 (17.0)	8 (11.1)	41 (18.9)	
Middle	174 (60.2)	42 (58.3)	132 (60.8)	
Low	66 (22.8)	2 (30.6)	44 (20.3)	
Income (monthly)				
Level 1 < €1,350	28 (9.7)	8 (11.3)	20 (9.2)	0.82
Level 2 ≥ €1,350 to < €3,600	113 (39.1)	29 (40.8)	84 (38.5)	
Level 3 ≥ €3,600 to < €5,250	93 (32.2)	23 (32.4)	70 (32.1)	
Level 4 ≥ €5,250	55 (19.0)	11 (15.5)	44 (20.2)	

Table 3.14 Socio-demographic characteristics by health care literacy (HC-HL)  
status Values are numbers and percentages in brackets

## Results

Table 3.14 shows the results of the health care index (HC-HL). As assumptions were not met i.e. there were fewer than 5 participants in one or more cells, it was not possible to test for statistically significant differences in health literacy levels in the demographic characteristics of education, employment, ethnicity, smoking status and social status. To summarize no statistically significant differences in health care literacy were found across the remaining demographic characteristics.

### *Key findings*

A higher percentage of those with limited health care literacy had parents who were born in Ireland, compared with those who had adequate literacy, 84.7% versus 71.5% respectively. A lower percentage of those with limited health care literacy exercised a few times a week or more compared to those with adequate literacy, 42.3% versus 52.1%. Conversely a higher percentage of those with limited health care literacy exercised a few times a month or less compared to those with adequate literacy, 50.7% versus 39.2%. Differences were not statistically significant.

There was a lower percentage of those with normal BMI in the limited health care literacy group compared to the group with adequate literacy, 35.9% versus 55.3%. There were no statistically significant differences between groups. There was a lower percentage of those with limited health care literacy who rated their own health as very good compared to those with adequate health care literacy 35.2% versus 47%. While not significant the p value for between group differences in self-rated health and health care category was 0.06. A higher percentage of those with limited health care literacy perceived their social status as low compared with those with adequate literacy, 30.6% versus 20.3%. Conversely a lower percentage of those with limited health care literacy perceived their social status as high compared with those with adequate literacy, 11.1% versus 18.9%. None of these trends reach statistical significance in this index of health literacy.

## Results

### Disease Prevention Literacy Index (DP-HL)

	All	Limited health literacy	Adequate health literacy	P Value
All	294 (100)	109 (35.2)	185 (69.7)	
Education				
Lower secondary or less	7 (2.4)	2 (1.9)	5 (2.7)	
Upper or post-secondary	57 (19.7)	21 (19.4)	36 (19.8)	
Third level	226 (77.9)	84 (78.7)	141 (77.5)	
Employment status				
Full-time employment	191 (65.6)	78 (72.2)	113 (61.7)	
Part-time employment	34 (11.7)	11 (10.2)	23 (12.6)	
Self-employed	13 (4.5)	5 (4.6)	8 (4.4)	
Unemployed	17 (5.8)	1 (0.9)	16 (8.7)	
Full-time homemaker or carer	31 (10.7)	12 (11.1)	19 (10.4)	
Student or on work experience	5 (1.7)	1 (0.9)	4 (2.2)	
Parental ethnic background				
Both parents born in Ireland	218 (74.4)	91 (83.5)	127 (69.0)	0.05
One parent born in Ireland	19 (6.5)	5 (4.6)	14 (7.6)	
Both parents born in another EU member state	36 (12.3)	8 (7.3)	28 (15.2)	
Both parents born outside of EU	20 (6.8)	5 (4.6)	15 (8.2)	
Exercise				
A few times a week or more	144 (50.0)	49 (45.8)	95 (52.5)	0.13
A few times a month or less	120 (41.7)	52 (48.6)	68 (37.6)	
Not able to exercise	24 (8.3)	6 (5.6)	18 (9.9)	
Smoking				
Never smoked	181 (61.8)	59 (54.1)	122 (66.3)	0.07
Former smoker	100 (34.1)	43 (39.4)	57 (31.0)	
Current smoker	12 (4.1)	7 (6.4)	5 (2.7)	
BMI				
Normal	146 (53.7)	54 (53.5)	92 (53.7)	0.99
Overweight	80 (29.4)	30 (29.7)	50 (29.2)	
Obese	46 (16.9)	17 (16.8)	29 (17.0)	
Health Insurance				
Private	170 (58.0)	62 (56.9)	108 (58.7)	0.74
Public	60 (20.5)	21 (19.3)	39 (21.2)	
None	63 (21.5)	26 (23.9)	37 (20.1)	
Self-rated health status				
Very good	128 (44.1)	41 (38.0)	87 (47.8)	0.16
Good	147 (50.7)	59 (54.6)	88 (48.4)	
Fair or Poor	15 (5.2)	8 (7.4)	7 (4.8)	
Social status (self-rated)				
High	49 (17.0)	14 (13.2)	35 (19.1)	0.19
Middle	173 (59.9)	62 (58.5)	111 (60.7)	
Low	67 (23.2)	30 (28.3)	37 (20.2)	
Income (monthly)				
Level 1 < €1,350	29 (10.0)	10 (9.3)	19 (10.0)	0.55
Level 2 ≥ €1,350 to < €3,600	112 (38.8)	47 (43.5)	65 (35.9)	
Level 3 ≥ €3,600 to < €5,250	93 (32.2)	34 (31.5)	59 (32.6)	
Level 4 >= €5,250	55 (19.0)	17 (15.7)	38 (21.0)	

Table 3.15 Socio-demographic characteristics by disease prevention literacy index (DP-HL) Values are number (percentage)

## Results

Table 3.15 shows the results of the disease prevention literacy index (DP-HL). As assumptions were not met i.e. there were fewer than 5 participants in one or more cells, it was not possible to test for statistically significant differences in health literacy levels in the demographic characteristics of education and employment.

### *Key findings*

There were no significant between group differences in employment categories in those with limited and those with adequate disease prevention literacy. A higher percentage of those with limited disease prevention literacy had parents who were born in Ireland, compared with those who had adequate literacy, 83.5% versus 69% respectively. Differences were not statistically significant. A higher percentage of those with limited disease prevention literacy were current smokers compared to those with adequate literacy, 6.4% versus 2.7%. This difference did not reach statistical significance.

There was a lower percentage of those with limited disease prevention literacy who rated their own health as very good compared to those with adequate literacy 38% versus 47.8%. Differences did not reach statistical significance. A higher percentage of those with limited disease prevention literacy perceived their social status as low compared with those with adequate literacy, 28.3% versus 20.2%. Differences did not reach statistical significance. A lower percentage of those in the highest income level compared to the adequate literacy group, 15.7% versus 21%. Differences did not reach statistical significance.

In summary while there were no significant between group differences in socio-demographic characteristics across the disease prevention literacy index there were trends across a number of factors, whereby limited health literacy in this index was more prevalent in those whose

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characteristics categorised them in a lower (rather than higher) socio-economic status.

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### *Health Promotion Literacy Index (HP-HL)*

	All	Limited health literacy	Adequate health literacy	P Value
All	293 (100)	128 (41.3)	165 (53.2)	
Education				
Lower secondary or less	7 (2.4)	3 (2.4)	4 (2.5)	
Upper or post-secondary	57 (19.7)	22 (17.5)	35 (21.5)	
Third level	225 (77.9)	101 (80.2)	124 (76.1)	
Employment status				
Full-time employment	191 (65.9)	89 (70.6)	102 (62.2)	
Part-time employment	34 (11.7)	15 (11.9)	19 (11.6)	
Self-employed	12 (4.1)	4 (3.2)	8 (4.9)	
Unemployed	17 (5.9)	4 (3.2)	13 (5.9)	
Full-time homemaker or carer	31 (10.7)	14 (11.1)	17 (10.4)	
Student or on work experience	5 (1.7)	0 (0.0)	5 (3.0)	
Parental ethnic background				
Both parents born in Ireland	218 (74.7)	102 (80.3)	116 (70.3)	0.27
One parent born in Ireland	19 (6.5)	7 (5.5)	12 (7.3)	
Both parents born in another EU member state	36 (12.3)	12 (9.4)	24 (14.5)	
Both parents born outside of EU	19 (6.5)	6 (4.7)	13 (7.9)	
Exercise				
A few times a week or more	143 (49.8)	61 (48.8)	82 (50.6)	0.13
A few times a month or less	120 (41.8)	54 (43.2)	66 (40.7)	
Not able to exercise	24 (8.4)	10 (8.0)	14 (8.6)	
Smoking				
Never smoked	180 (61.6)	80 (63.0)	100 (60.6)	
Former smoker	100 (34.2)	39 (30.7)	61 (37.0)	
Current smoker	12 (4.1)	8 (6.3)	4 (2.4)	
BMI				
Normal	144 (53.1)	56 (47.5)	88 (57.5)	0.26
Overweight	80 (29.5)	39 (33.1)	41 (26.8)	
Obese	47 (17.3)	23 (19.5)	24 (15.7)	
Health Insurance				
Private	168 (57.7)	74 (58.3)	94 (57.0)	0.74
Public	60 (20.5)	26 (20.5)	34 (20.6)	
None	64 (21.9)	27 (21.3)	37 (22.4)	
Self-rated health status				
Very good	127 (43.9)	44 (34.9)	83 (50.9)	0.02
Good	146 (50.5)	73 (57.9)	73 (44.8)	
Fair or Poor	16 (5.5)	9 (7.1)	7 (4.3)	
Social status (self-rated)				
High	49 (16.9)	16 (12.7)	33 (20.1)	0.24
Middle	174 (60.0)	79 (62.7)	95 (57.9)	
Low	67 (23.1)	31 (24.6)	36 (22.0)	
Income (monthly)				
Level 1 < €1,350	29 (10.0)	16 (12.6)	13 (8.0)	0.19
Level 2 ≥ €1,350 to < €3,600	113 (39.0)	49 (39.3)	64 (39.3)	
Level 3 ≥ €3,600 to < €5,250	93 (32.1)	44 (34.6)	49 (30.1)	
Level 4 ≥ €5,250	55 (19.0)	18 (14.2)	37 (22.7)	

Table 3.16 Demographic characteristics by health promotion literacy status  
(HP-HL) Values are numbers and percentages in brackets

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Table 3.16 shows the results of the health promotion literacy index (HP-HL). As assumptions were not met i.e. there were fewer than 5 participants in one or more cells, it was not possible to test for statistically significant differences in health promotion literacy levels in the demographic characteristics of education, employment and smoking status.

### *Key findings*

A higher percentage of those with limited disease prevention literacy had parents who were born in Ireland, compared with those who had adequate literacy, 80.3% versus 70.3%. Differences did not reach statistical significance. A higher percentage of those with limited health promotion literacy were current smokers compared to those with adequate literacy, 6.4% versus 2.4%. The percentage of participants in the limited health promotion literacy group who had a normal BMI was lower when compared with the adequate literacy group, 47.5% versus 57.5%; this difference did not reach statistically significance.

There was a lower percentage of those with limited health promotion literacy who rated their own health as very good compared to those with adequate literacy 34.9% versus 50.9%. Overall between group differences were significant with a p value of 0.02. A lower percentage of those in the limited health promotion literacy group were in the highest income level compared to the adequate literacy group, 14.2% versus 22.7%. Conversely a higher percentage of those in the limited health promotion literacy group were in the lowest income group compared with the adequate literacy group, 12.6% versus 8%. Differences did not reach statistical significance.

In summary there were trends across a number of socio-demographic factors, whereby limited health literacy in this index was more prevalent in those whose characteristics categorised them in a lower (rather than higher) socio-economic status. Differences were statistically significant in self-rated health status.

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### 3.5 Health literacy, pregnancy-related factors and adverse pregnancy outcomes

Pre-pregnancy folic acid, breast feeding (first feed), pregnancy complications and adverse pregnancy outcomes were calculated in limited and adequate literacy levels of functional health literacy, general health literacy and the sub-indices of the HLS results. Where assumptions were met Chi square test was carried out and p values were calculated. Tables summarizing the results are presented in this section.

#### *Functional Health Literacy*

	All Number (%)	Limited health literacy Number (%)	Adequate health literacy Number (%)	p Value	Odds ratio (CI) <sup>^</sup> adequate compared to limited FHL
All	297 (100)	75 (25.3)	222 (74.7)		
<b>Pregnancy related factors</b>					
Pre-pregnancy folic acid	181 (64.2)	38 (53.5)	143 (67.8)	0.04	0.95 (0.49-1.82)
Breast feed (first feed)	190 (69.6)	40 (60.6)	150 (72.5)	0.09	1.82 (0.89-3.73)
<b>Adverse pregnancy outcomes</b>					
GDM	30 (10.3)	12 (16.7)	18 (6.2)	0.06	0.80 (0.31-2.08)
Gestational Hypertension	17 (6.0)	6 (8.6)	11 (5.1)	0.45	0.46 (0.15-1.40)
Pre-eclampsia	4 (1.4)	3 (4.3)	1 (0.5)		0.08 (0.01-0.82)
Caesarean delivery	101 (35.4)	25 (35.7)	76 (35.3)	1.0	1.05 (0.55-1.97)
Composite adverse maternal outcomes*	125 (43.9)	71 (50.7%)	89 (41.6)	0.23	0.82 (0.24-2.78)
Prematurity	16 (5.6)	4 (5.7)	12 (5.6)		0.90 (0.25-3.20)
Macrosomia	46 (16.1)	11 (15.7)	35 (16.3)	1.0	0.85 (0.37-1.96)
LGA	31 (10.9)	9 (12.9)	22 (10.2)	0.69	0.75 (0.29-1.91)
SGA	23 (8.1)	4 (5.7)	19 (8.8)		2.32 (0.68-7.86)
NICU admission	12 (4.2)	4 (5.7)	8 (3.7)		0.84 (0.19-3.61)
Composite adverse neonatal outcomes**	94 (33)	23 (32.9)	71 (33)		1.06 (0.56-2.03)

Table 3.17 Pregnancy-related factors and adverse outcomes by functional health literacy status

(NVS) \*One or more adverse maternal outcome (GDM, gestational hypertension, pre-eclampsia, Caesarean section). \*\*One or more adverse neonatal outcome (prematurity, macrosomia, LGA, SGA, NICU admission). FHL functional health literacy

<sup>^</sup>Odds ratios after adjustment for income, education and parental ethnic background

#### *Functional health literacy and pre-pregnancy folic acid*

Pre-pregnancy folic acid treatment was recorded in 64.2% of women in the study (Table 3.17). There was a lower percentage of those with limited functional health literacy who took pre-pregnancy folic acid compared with

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those who had adequate literacy, 53.5% versus 67.8%. This was statistically significant with a p value of 0.04.

### *Functional health literacy and breast feeding (first feed)*

The first feed was recorded as a breast feed in 69.9% of cases. A lower percentage of those with limited functional health literacy breast fed the first feed compared with those with adequate literacy, 60.6% versus 72.5%. This difference did not reach statistical significance.

### *Functional health literacy and GDM*

In the limited functional health literacy group 16.7% had GDM, while in the group with adequate literacy 6.2% had GDM. This difference was close to statistical significance ( $p = 0.06$ ).

### *Functional health literacy and Gestational Hypertension*

The rate of gestational hypertension was higher in the group with limited functional health literacy than in the group with adequate functional health literacy, 8.6% versus 5.1%. This did not reach statistical significance.

### *Functional health literacy and Pre-eclampsia*

There were only 4 cases of pre-eclampsia in total, 3 in the limited functional health literacy group and 1 in the adequate functional literacy group.

### *Functional health literacy and Caesarean section delivery*

Caesarean section delivery was performed in 35.4% of all deliveries. There was no difference in the rates of Caesarean section delivery in those with limited compared to those with adequate functional health literacy.

### *Functional health literacy and adverse maternal outcomes*

Overall 125 participants (43.9%) had one or more adverse maternal outcomes. A higher percentage of those with limited functional health literacy had adverse maternal outcomes (50.7%) compared with those with

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adequate functional health literacy (41.6%). This difference did not reach statistical significance.

### *Functional health literacy and Prematurity*

The rate of prematurity (< 37 weeks) was 5.6% overall. There was no difference in the rate of prematurity in those with limited compared to those with adequate functional health literacy.

### *Functional health literacy and Macrosomia*

Macrosomia was present in 16.1% of all neonates. Rates were similar in those with limited and adequate functional health literacy, 15.7% versus 16.3%.

### *Functional health literacy and LGA*

LGA was present in 10.9% of all neonates. Rates were higher in those with limited functional health literacy compared to those with adequate functional literacy, 12.9% versus 10.2%. This difference was not statistically significant.

### *Functional health literacy and SGA*

SGA was present in 8.1% of all neonates. The rate was lower in those with limited functional health literacy compared to those with adequate functional literacy, 5.7% versus 8.8%. This difference was not statistically significant.

### *Functional health literacy and NICU admission*

Admission to NICU occurred in 4.2% of neonates. The rate was higher in those with limited compared to those with adequate functional health literacy, 5.7% versus 3.7%.

### *Functional health literacy and adverse neonatal outcomes*

Overall 94 neonates (33%) had one or more adverse outcomes. Rates were similar in limited and adequate functional health literacy groups.

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A binary logistic regression analysis on pregnancy-related factors and pregnancy outcomes was conducted with functional health literacy and the variables found to significantly predict functional health literacy were entered as covariates (table 3.11). The variables entered in the analysis were, therefore, functional health literacy, household income, parental ethnic background and education. The odds ratios and confidence intervals are reported in table 3.17. The odds ratios presented represent the odds of those with adequate functional health literacy having the outcome compared to those with limited functional health literacy.

Following adjustment for income, education and parental ethnic background there was no longer a significant association between functional health literacy category and pre-pregnancy folic acid. Odds ratio of breast feeding (first feed) was 1.82 but this was not significant as the confidence interval was 0.89-3.73. All of the (individual) adverse pregnancy outcomes, with the exception of Caesarean section delivery and SGA, had odds of less than 1 occurring in those with adequate compared to those with limited functional health literacy. Odd ratio was significant only for pre-eclampsia (OR 0.08 and CI 0.01-0.82). The number of participants with this complication was small, 4 in total. Composite adverse maternal and composite neonatal outcomes had odds ratio just greater than 1, (1.05 and 1.06 respectively) and these were not significant.

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### *General Health literacy index (GEN HL)*

Table 3.18 show results of pregnancy factors and adverse outcomes in participants with limited and adequate health literacy as measured with the GEN HL index.

	All	Limited HL	Adequate HL	P Value
All	293 (100)	113 (38.6)	180 (61.4)	
<b>Pregnancy related factors</b>				
Pre-pregnancy folic acid	178 (64.0)	63 (58.9)	115 (67.3)	0.19
Breast feed (first feed)	186 (69.1)	71 (68.3)	115 (69.7)	0.91
<b>Adverse pregnancy outcomes</b>				
GDM	28 (9.7)	12 (10.6)	16 (9.1)	0.83
Gestational Hypertension	17 (6.0)	5 (4.6)	12 (7.0)	0.57
Pre-eclampsia	4 (1.4)	2 (1.8)	2 (1.2)	
Caesarean delivery	99 (35.2)	37 (33.9)	62 (36.0)	0.82
Composite adverse maternal outcomes*	121 (43.1)	44 (40.4)	77 (44.8)	0.55
Prematurity	16 (5.7)	2 (1.8)	14 (8.1)	
Macrosomia	45 (16.4)	21 (19.3)	24 (13.9)	0.31
LGA	31 (11.0)	9 (8.2)	22 (12.8)	0.32
SGA	23 (8.1)	10 (9.2)	13 (7.6)	0.79
NICU admission	12 (4.3)	5 (4.6)	7 (4.1)	1.00
Composite adverse neonatal outcomes**	93 (33.1)	35 (32.1)	58 (33.7)	0.88

Table 3.18 Pregnancy-related factors and adverse outcomes by general health literacy status  
 \*One or more adverse maternal outcome (GDM, gestational hypertension, pre-eclampsia, Caesarean section). \*\*One or more adverse neonatal outcome (prematurity, macrosomia, LGA, SGA, NICU admission). Values are number and percentages in brackets

### *Key findings*

Overall there were no significant differences in adverse pregnancy outcomes in the adequate and limited general health literacy groups. There was a trend whereby a lower percentage of those with limited health literacy took pre-pregnancy folic acid compared with those who had adequate literacy, 58.9% versus 67.3%. Similar percentages of those with limited and adequate general health literacy had adverse maternal outcomes.

Overall there were no significant differences in individual and composite adverse neonatal outcomes in the general health literacy categories of

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adequate and limited literacy. Only 2 (1.8%) neonates born of women in the limited health literacy group were premature compared with 14 (8.1%) in the group with adequate health literacy. Macrosomia occurred more frequently in the group with limited health literacy compared to the group with adequate health literacy, 19.3% versus 13.9%. The rate of LGA was lower in the group with limited health literacy compared with those with adequate functional literacy, 8.2% versus 12.8%. This difference was not statistically significant. The rate of SGA was lower in those with limited health literacy compared to those with adequate literacy, 8.2% versus 12.8% respectively. Overall 93 neonates (33.1%) had one or more adverse outcomes. Rates were similar in limited and adequate functional health literacy groups.

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### *Health Care Literacy Index (HC-HL)*

	All	Limited health literacy	Adequate health literacy	P Value
All	293 (100)	113 (38.6)	180 (61.4)	
<b>Pregnancy related factors</b>				
Pre-pregnancy folic acid	179 (64.2)	35 (53.0)	144 (67.6)	0.04
Breast feed (first feed)	187 (69.3)	44 (65.7)	143 (70.4)	0.56
<b>Adverse pregnancy outcomes</b>				
GDM	29 (10.0)	7 (9.9)	22 (10.1)	0.95
Gestational Hypertension	17 (6.0)	6 (8.7)	11 (5.2)	0.29
Pre-eclampsia	4 (1.4)	2 (2.9)	2 (0.9)	
Caesarean delivery	99 (35.1)	18 (26.1)	81 (38.0)	0.07
Composite adverse maternal outcomes*	122 (43.3)	24 (34.8)	98 (46)	0.13
Prematurity	16 (5.7)	2 (2.9)	14 (6.6)	
Macrosomia	45 (16.0)	12 (17.4)	33 (16.0)	0.71
LGA	31 (11.0)	4 (5.8)	27 (12.7)	
SGA	23 (8.2)	9 (13.0)	14 (6.6)	0.15
NICU admission	12 (4.3)	5 (7.2)	7 (3.3)	0.28
Composite adverse neonatal outcomes**	93 (33)	25 (36.2)	68 (31.9)	0.61

Table 3.19 Pregnancy-related factors and adverse pregnancy outcomes by health care literacy status \*One or more adverse maternal outcome (GDM, gestational hypertension, pre-eclampsia, Caesarean section). \*\*One or more adverse neonatal outcome (prematurity, macrosomia, LGA, SGA, NICU admission). Values are number and percentages in brackets

Table 3.19 shows results of pregnancy factors and adverse outcomes in participants with limited and adequate health literacy as measured with the HC-HL index. I tested for statistical significance between frequencies in a number of variables who met the assumptions for Chi Square test (table 26). The rate of pre-pregnancy folic acid was lower in those with limited compared to those with adequate literacy in this index, 53% versus 67.6%. This was statistically significant with a p value of 0.04. Differences in the other variables did not reach statistical significance.

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### *Disease Prevention Literacy Index (DP-HL)*

	All	Limited health literacy	Adequate health literacy	P Value
All	294 (100)	109 (35.2)	185 (69.7)	
<b>Pregnancy related factors</b>				
Pre-pregnancy folic acid	179 (64.2)	62 (59.6)	117 (66.9)	0.27
Breast feed (first feed)	187 (69.3)	70 (70.0)	117 (68.8)	0.95
<b>Adverse pregnancy outcomes</b>				
GDM	29 (10.0)	9 (8.3)	20 (11.1)	0.56
Gestational Hypertension	17 (6.0)	6 (5.7)	11 (6.3)	1.0
Pre-eclampsia	4 (1.4)	2 (1.9)	2 (1.1)	
Caesarean delivery	99 (35.1)	35 (33.3)	64 (36.2)	0.72
Composite adverse maternal outcomes*	122 (43.3)	40 (38.1)	82 (46.3)	0.22
Prematurity	16 (5.7)	4 (3.8)	12 (6.8)	
Macrosomia	45 (16.0)	17 (16.2)	28 (15.8)	1.0
LGA	31 (11.0)	8 (7.6)	23 (13.0)	0.23
SGA	23 (8.2)	8 (7.6)	15 (8.5)	0.98
NICU admission	12 (4.3)	4 (3.8)	8 (4.5)	
Composite adverse neonatal outcomes**	93 (33)	30 (28.6)	63 (35.6)	0.28

Table 3.20 Pregnancy-related factors, adverse pregnancy outcomes by disease prevention literacy status (DP HL) \*One or more adverse maternal outcome (GDM, gestational hypertension, pre-eclampsia, Caesarean section). \*\*One or more adverse neonatal outcome (prematurity, macrosomia, LGA, SGA, NICU admission). Values are number (percentage)

Table 3.20 presents results of pregnancy factors and adverse outcomes in participants with limited and adequate health literacy as measured with the DP-HL index. I tested for statistical significance between frequencies in a number of variable who met the assumptions for Chi Square test but did not find any statistically significant differences between the group with limited and the group with adequate literacy in the disease prevention literacy index.

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### *Health Promotion Index (HP-HL)*

Table 3.21 show results of pregnancy factors and adverse outcomes in participants with limited and adequate health literacy as measured with the HP-HL index.

	All	Limited health literacy	Adequate health literacy	P Value
All	293 (100)	128 (41.3)	165 (53.2)	
<b>Pregnancy related factors</b>				
Pre-pregnancy folic acid Yes	177 (63.7)	75 (62.0)	102 (65.0)	0.69
Breast feed (first feed)	186 (69.1)	80 (69.0)	106 (69.3)	1.0
<b>Adverse pregnancy outcomes</b>				
GDM	28 (9.7)	13 (10.1)	15 (9.4)	0.94
Gestational Hypertension	17 (6.1)	6 (4.9)	11 (7.0)	0.63
Pre-eclampsia	4 (1.4)	3 (2.4)	1 (0.6)	
Caesarean delivery	100 (35.6)	46 (37.4)	54 (34.2)	0.66
Composite adverse maternal outcomes*	122 (43.4)	54 (43.9)	68 (43)	0.98
Prematurity	16 (5.7)	3 (2.4)	13 (8.2)	
Macrosomia	45 (16.0)	20 (16.3)	25 (15.8)	1.0
LGA	31 (11.0)	12 (9.8)	19 (12.0)	0.68
SGA	23 (8.2)	12 (9.8)	11 (7.0)	0.53
NICU admission	12 (4.3)	7 (5.7)	5 (3.2)	0.46
Composite adverse neonatal outcomes**	93 (33.1)	39 (31.7)	54 (34.2)	0.76

Table 3.21 Pregnancy-related factors and adverse pregnancy outcomes by health promotion literacy status \*One or more adverse maternal outcome (GDM, gestational hypertension, pre-eclampsia, Caesarean section). \*\*One or more adverse neonatal outcome (prematurity, macrosomia, LGA, SGA, NICU admission). Data are expressed as number and percentages in brackets

I tested for statistical significance between frequencies in a number of variables who met the assumptions for Chi Square test but did not find any statistically significant differences between the group with limited and the group with adequate literacy in the health promotion literacy index (table 3.21).

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### **3.6 Health literacy measures as continuous variables, socio-demographic factors and pregnancy outcomes**

As both the NVS and HLS measures provide literacy scores as continuous variables, I did an additional analysis on health literacy expressed as continuous variables. The results of functional health literacy (NVS) and the GEN-HL index are presented.

#### *Functional health literacy as a continuous variable analysis*

In table 3.22 results are presented as median and IQR and p values were calculated by conducting Kruskal-Wallis testing for between group differences in scores.

#### Notable findings

Functional health literacy scores increased as education attainment level increased and the differences reached statistical significance with a p value of 0.001. Employment status data revealed lower scores in those who were unemployed and students/on work experiences groups, although the number in the latter category was small at 5. Differences across the categories of employment reached statistical significance with a p value of 0.001. Parental ethnic background categories had variable median scores with those with one or both parents from non-EU countries having lower scores compared to those with one or both parents born in Ireland. Differences were statistically significant between groups. Those who were current smokers had lower functional health literacy compared to non-smokers and this was statistically significant with a p value of 0.04. Participants with private health insurance had higher functional health literacy scores than those with public or no insurance and between group differences were statistically significant with a p value of 0.001.

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<b>Demographic characteristics</b>	<b>n</b>	<b>Median (IQR)</b>	<b>P value</b>
Education			
Lower secondary or less	8	2.5 (2.-4.5)	0.001
Upper secondary or post-secondary	58	4 (3-5)	
Third level	227	5 (4-6)	
Employment status			
Full-time employment	192	5 (4-6)	0.001
Part-time employment	36	4.5 (3-6)	
Self-employed	13	5 (5-6)	
Unemployed	17	3 (2-4)	
Full-time homemaker or carer	31	5 (3.5-5)	
Student or on work experience	5	3 (2-3)	
Parental ethnic background			
Both parents born in Ireland	220	5 (4-6)	0.001
One parent born in Ireland	19	5 (3.5-5.5)	
Both parents born in another EU member state	37	4 (3-5)	
Both parents born outside of EU	20	3 (2.5-4)	
Exercise			
A few times a week or more	145	5 (3-6)	0.1
A few times a month or less	122	5 (4-6)	
Not able to exercise	24	5 (4-6)	
Smoking			
Never smoked	183	5 (4-6)	0.04
Former smoker	101	5 (4-6)	
Current smoker	12	3 (2-4.5)	
BMI			
Normal	147	5 (4-6)	0.9
Overweight	81	5 (3-6)	
Obese	47	5 (4-6)	
Health Insurance			
Private	170	5 (4-6)	0.001
Public	61	4 (3-5)	
None	65	4 (3-6)	
Self-rated health status			
Very good	128	5 (3-6)	0.38
Good	148	5 (3-5.5)	
Fair or Poor	17	5 (4-6)	
Social status (self-rated)			
High	49	5 (4-5)	0.02
Middle	174	5 (4-6)	
Low	67	4 (3-5)	
Income (monthly)			
Level 1 < €1,350	29	3 (2-4)	0.001
Level 2 ≥ €1,350 to < €3,600	113	5 (3-5)	
Level 3 €3,600 to < €5,250	93	5 (4-6)	
Level 4 >= €5,250	55	5 (4-6)	

Table 3.22 Functional health literacy scores by socio-demographic factor categories

Values are median and IQR in brackets

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Self-perceived social status data shows that those who rate themselves as low on the scale have lower functional health literacy and between group differences reached statistical significance. Finally functional health literacy scores were lower in those on the lowest income level and between group differences were statistically significant with a p value of 0.001.

### *Pregnancy-related factors and adverse outcomes*

The NVS data is presented as median and a p value is calculated from the Mann-Whitney U test (table 3.23). From this table participants who were taking folic acid prior to pregnancy had statistically significant higher NVS scores compared to those who did not take folic acid.

	Yes/Present	No/Absent	P Value
<b>Pregnancy related factors</b>			
Pre-pregnancy folic acid	5 (4-6)	4 (3-5)	0.02
Breast feed (first feed)	5 (4-6)	4 (3-5)	0.001
<b>Adverse pregnancy outcomes</b>			
GDM	4 (3-6)	5 (4-6)	0.09
Gestational Hypertension	4 (3-5)	5 (4-6)	0.38
Pre-eclampsia	3 (3-4)	5 (4-6)	0.10
Caesarean delivery	5 (4-6)	5 (4-6)	0.53
Composite adverse maternal outcomes*	5 (3-6)	5 (4-6)	0.21
Prematurity	4 (3.5-5)	5 (4-6)	0.27
Macrosomia	4.5 (4-5)	5 (4-6)	0.38
LGA	4 (3-5)	5 (4-6)	0.05
SGA	5 (4-5.5)	5 (3-6)	0.76
NICU admission	5 (4-6)	5 (4-6)	0.65
Composite adverse neonatal outcomes**	5 (3.75-5)	5 (4-6)	0.14

Table 3.23 Functional health literacy scores by pregnancy-related factors and adverse outcomes status \* One or more adverse maternal outcome (GDM, gestational hypertension, pre-eclampsia, Caesarean section). \*\*One or more adverse neonatal outcome (prematurity, macrosomia, LGA, SGA, NICU admission). Values are median and IQR in brackets

Similarly the NVS score was statistically higher in those who breast fed compared with those who did not breast feed. Median MVS scores were

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lower in those with GDM, gestational hypertension, pre-eclampsia, caesarean delivery, macrosomia and LGA, compared with those who did not have these complications. These differences did not reach statistical significance.

## Results

### *GEN Health Literacy Index expressed as a continuous variable analysis*

<b>Demographic characteristics</b>	<b>N</b>	<b>Mean (SD)</b>	<b>P value</b>
Education			
Lower secondary or less	7	34.4 (4.0)	0.6
Upper secondary or post-secondary	57	35.7 (6.0)	
Third level	225	34.9 (5.8)	
Employment status			
Full-time employment	191	34.6 (5.8)	0.11
Part-time employment	34	36.0 (6.7)	
Self-employed	12	36.5 (4.8)	
Unemployed	17	38.0 (5.9))	
Full-time homemaker or carer	31	33.9 (5.5)	
Student or on work experience	5	27.2 (3.3)	
Ethnicity No.			
Both parents born in Ireland	218	34.5 (5.7)	0.03
One parent born in Ireland	19	35.3 (4.4)	
Both parents born in another EU member state	36	37.3 (6.6)	
Both parents born outside of EU	19	36.8 (5.8)	
Exercise			
A few times a week or more	144	35.4 (5.7)	0.34
A few times a month or less	119	34.4 (6.1)	
Not able to exercise	24	35.6 (5.1)	
Smoking			
Never smoked	181	35.2 (5.7)	0.08
Former smoker	99	35.3 (6.1)	
Current smoker	12	31.4 (5.1)	
BMI			
Normal	145	35.4 (5.7)	0.49
Overweight	80	34.4 (6.0)	
Obese	46	34.8 (5.6)	
Health Insurance			
Private	169	35.0 (5.2)	0.96
Public	60	35.2 (6.5)	
None	63	35.0 (5.8)	
Self-rated health status			
Very good	127	36.0 (6.0)	0.04
Good	147	34.4 (5.6)	
Fair or Poor	15	33.5 (5.5)	
Social status (self-rated)			
High	49	36.1 (5.8)	0.06
Middle	173	35.3 (5.4)	
Low	67	33.7 (6.6)	
Income (monthly)			
Level 1 < €1,350	29	34.2 (6.5)	0.1
Level 2 €1,350 to less than €3,600	112	34.9 (5.9)	
Level 3 €3,600 to less than €5,250	93	34.4 (5.6)	
Level 4 >= €5,250	55	36.8 (5.7)	

Table 3.24 General health literacy scores by socio-demographic factor categories

Values are mean and SD in brackets

## Results

In table 3.25 results are presented as mean and SD and p values were calculated by conducting a one-way between-groups analysis of variance testing for between group differences in scores.

### Notable findings

Differences in health literacy reached statistical significance in parental ethnic background and self-rated health status categories. In the ethnic categories those who had one or both parents born outside of the EU had higher health literacy compared to those with one or both parents born in Ireland. The differences across categories were statistically significant with a p value of 0.03.

Those who rated their health as very good had higher health literacy compared to those who rated their health as good, with health literacy lowest in those who rated their health as fair/poor. Differences between groups were statistically significant with a p value of 0.04.

### *Pregnancy-related factors and adverse outcomes*

The GEN-HL index data is presented in table 3.24. Independent t-test was used to test for statistically significant differences between the groups.

The results show no statistically significant differences in health literacy scores between the groups across the pregnancy-related factors and outcomes.

## Results

	<b>Yes/Present</b>	<b>No/Absent</b>	<b>P Value</b>
<b>Pregnancy related factors</b>			
Pre-pregnancy folic acid	35.2 (5.7)	34.6 (5.9)	0.45
Breast feed (first feed)	35.2 (6.1)	34.8 (5.0)	0.53
<b>Adverse pregnancy outcomes</b>			
GDM	35.4 (5.8)	34.9 (5.6)	0.67
Gestational Hypertension	35.1 (4.6)	35.0 (5.8)	0.94
Pre-eclampsia	33.6 (6.0)	35.0 (5.8)	0.67
Caesarean delivery	35.2 (5.3)	34.9 (6.0)	0.69
Composite adverse maternal outcomes*	35.6 (5.5)	34.7 (5.9)	0.19
Prematurity	37.4 (4.2)	34.9 (5.8)	0.09
Macrosomia	35.1(6.0)	35.0 (5.7)	0.98
LGA	36.8 (6.0)	34.8 (5.7)	0.07
SGA	34.3 (5.2)	35.1 (5.8)	0.52
NICU admission	33.5 (4.5)	35.1 (3.2)	0.34
Composite adverse neonatal outcomes**	35.4 (5.5)	34.9 (5.9)	0.46

Table 3.25 General health literacy scores by pregnancy-related factors and adverse outcomes status \*One or more adverse maternal outcome (GDM, gestational hypertension, pre-eclampsia, Caesarean section). \*\*One or more adverse neonatal outcome (prematurity, macrosomia, LGA, SGA, NICU admission). Values are mean and standard deviation in brackets

### 3.7 Perceived Health Literacy and measured Health Literacy

#### *Functional health literacy and perceived health literacy*

Table 3.26 depicts the numbers and percentages of participants, when asked to rate their own health literacy, who rated this as low, adequate, above average and high. The data is presented for all participants and in the subgroups of those with limited and adequate functional health literacy.

<b>Perceived Health Literacy and Functional Health Literacy (NVS (U.K.))</b>			
<b>Perceived Health Literacy</b>	<b>All</b>	<b>Limited FHL</b>	<b>Adequate FHL</b>
Low	6 (2.0)	2 (2.8)	4 (1.8)
Adequate	169 (57.7)	50 (69.4)	119 (53.8)
Above average	73 (24.9)	11 (15.3)	73 (33.0)
High	45 (15.4)	9 (12.5)	36 (16.3)
Total	293 (100)	72 (100)	221 (100)

Table 3.26 Perceived Health Literacy by Functional Health Literacy status

Data represents numbers and percentages in brackets

Only 6 participants (2%) rated their health literacy as low, which contrasts with the findings of limited functional health literacy in 72 participants (24.6%). The majority of those with limited functional health literacy, 97.2%, did not perceive this to be the case and stated that their literacy skills were adequate (69.4%), above average (15.3%) or high (12.5%).

## Results

Perceived Health Literacy and HLS General Index			
Perceived Health Literacy	All	Limited GEN HL	Adequate GEN HL
Low	6 (2.1)	3 (2.6)	3 (1.7)
Adequate	166 (57.4)	78 (69.0)	88 (50.0)
Above average	72 (24.9)	24 (21.2)	48 (27.3)
High	45 (15.6)	8 (7.1)	37 (21.0)
Total	289 (100)	113 (100)	176 (100)

Table 3.27 Perceived Health Literacy by general health literacy status

Data represents numbers and percentages in brackets

Table 3.27 depicts the results of perceived health literacy and measured health literacy using the HLS, GEN-HL index. Data is presented for all participants and in the subgroups of those with limited and adequate health literacy. Only 6 participants (2.1%) perceived their health literacy as low, which contrasts with the finding of limited health literacy (GEN-HL index) found in 113 of 289 participants (39.1%). The majority of those with limited health literacy (97.4%) did not perceive this to be the case and stated that their literacy skills were adequate (69%), above average (21.2%) or high (7.1%).

## Section 4: Discussion

### 4.1 Main findings

#### *Prevalence of limited health literacy*

In my study I found limited functional health literacy in 25.3% of pregnant women, with 2.7% having a high likelihood and 22.6% a possibility of limited literacy, as measured by the NVS (U.K.). These pregnant women scored 3 or less, out of a total score of 6 in the NVS, indicating that they answered 50% or more of the questions incorrectly. Results indicate that 1 in 4 pregnant women in my study had limited reading, comprehension and numeracy skills.

The results of the EU HLS-Q show that the presence of limited health literacy was high at 38%, indicating that in excess of 1 in 3 participants scored in the inadequate or problematic categories in the general index (GEN-HL). This means that 38% of my sample of pregnant women, who were at risk of GDM, had limited general health literacy. The Gen-HL index (calculated from all 47 items in the scale), measures health literacy in the key competencies of accessing, understanding, appraising and applying information in the domains of health care, disease prevention and health promotion. Results from the 3 sub-indices namely health care (HC-HL), disease prevention (DP-HL) and health promotion (HP-HL) showed that the highest percentage of sufficient or excellent health literacy was in the HC-HL index and the lowest percentage was in the HP-HL index, at 75.5% and 56.31% respectively. The DP-HL index was in between the 2 other sub-indices, with 62.93% having sufficient or excellent literacy in this index.

#### *HC-HL index*

In general tasks that involve following medical instructions or finding where to get health information were rated as easier to do than tasks where judgement on quality and source of health information was

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required. For example only 1% rated following instructions from their doctor or pharmacist as difficult but 54.7% rated as difficult or very difficult the task of judging when they may need to get a second opinion from another doctor. Judging how reliable “information about illness in the media is” was rated as difficult or very difficult by two thirds of participants (66.8%) and 37.8% rated judging the advantages and disadvantages of different treatment options as difficult or very difficult. One in 5 found it difficult or very difficult to read the leaflets that come with their medicine.

### *DP-HL index*

Very few pregnant women rated how to find information on how to manage unhealthy behaviour as fairly or very difficult (2.7%); however 28.2% rated how to find information on how to manage mental health problems as fairly or very difficult. Forty two point three percent of participants found it difficult or very difficult to judge which vaccinations they may need. Similar to the question on judging ‘how reliable information about illness in the media is’ in the HC-HL index, a high percentage, namely 58.5% of participants found it difficult or very difficult to judge how reliable information in the media is on health risks. Judging when they may need to go to the doctor for a check-up or which health screens they might need was rated as difficult by approximately 1 in 5 participants.

### *HP-HL index*

More than half of the participants (58.8%) rated as fairly or very difficult to ‘find information on how their neighbourhood could be more health friendly’. Sixty five percent found it difficult to ‘find out about political changes that may affect health’ and 1 in 3 had difficulty understanding information on food packaging.

In summary a significant proportion of pregnant women in my study limited functional health literacy and limited general health literacy. This is reflected in the findings of items whereby participants had difficulty with

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health-related tasks, in particular, those which required or multiple steps in reasoning, such as finding, interpreting and making judgements on health-related information relevant to their health. This likely reflects a lack of education, training and/or practice in developing these types of skills in different domains of health, such as health-care, disease prevention and health promotion. It is also likely that these inadequate skills spill over into other domains such as navigation of the health services, ability to engage in conversations on health topics and the motivation to self-help, and seek out choices to maintain and improve health. These findings, in a sample of women at risk of GDM, are of relevance as education and self-management are core steps in the management of GDM. Those with limited health literacy are likely to require additional and/or more intensive support to achieve successful management of GDM, which has been shown to reduce the occurrence of adverse pregnancy outcomes (122, 127).

### *Limited health literacy and socio-demographic factors*

Both measures of health literacy, the NVS U.K. and the EU HLS-Q, were significantly associated with a number of socio-demographic factors. I found a significant association between functional health literacy and the following socio-demographic factors:

- Education attainment
- Employment status
- Income level
- Parental ethnic background
- Smoking status
- Health insurance status
- Self-rated social status

Functional health literacy was higher in those with higher educational attainment, earning a higher income and those who had a higher self-rated social status. By contrast functional health literacy was lower in those who were current smokers, whose parents were from non-EU countries and

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who were unemployed or in part-time employment. Participants with private health insurance were more likely to have adequate functional health literacy. Associations were stronger for income, education, employment status, parental ethnic background, health insurance status with p values of 0.001. P values were not as significant for smoking status ( $p=0.04$ ) and social status ( $p=0.02$ ).

General health literacy was significantly associated with the following socio-demographic factors:

- Self-rated health status
- Parental ethnic background

Participants who had one or both parents born outside of Ireland had higher mean scores than those who had one or both parents born in Ireland. This finding is in contrast to the functional health literacy results, which found lower NVS scores in those whose parents were born outside of Ireland. Self-rated health was significantly associated with general health literacy, whereby those who rated their health as very good or good had higher general health literacy scores compared with those who rated their health as fair or poor, with a p value of 0.04.

### *Predictors of Health Literacy*

My analysis found that 20.3% of the variance in functional health literacy was explained by income, education, social status, parental ethnic background and self-rated health. Household income, education and parental ethnic background significantly predicted functional health literacy. Household income and education positively predicted functional health literacy and parental ethnic background negatively predicted functional health literacy. These five factors only predicted 5.4% of the variance in general health literacy; of these social status and parental ethnic background were significant, and both positively predicted general health literacy.

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### *Adverse pregnancy outcomes*

There were 30 cases of GDM (10.3%) and 17 cases of gestational hypertension (6%) in my sample. Rates of polyhydramnios and pre-eclampsia were low, at 0.7% and 1.4% respectively. The Caesarean section rate was 35.4%. The most frequent adverse neonatal outcomes were macrosomia and LGA, at 16.1% and 10.9% respectively. Eight point one percent of neonates were SGA and 5.2% were born prematurely. Other adverse outcomes were rare and, in some cases, there were no neonates with the adverse outcome (neonatal hypoglycaemia, shoulder dystocia) in my study sample. Admission to NICU occurred in 4.2% of neonates.

### *Pregnancy-related factors, adverse pregnancy outcomes and health literacy*

There was a significant positive association between taking pre-pregnancy folic acid and functional health literacy. Following adjustment for income, education and parental ethnic background this association was no longer significant. This result can be interpreted as indicating that functional health literacy is associated with pre-pregnancy folic acid but that confounders are also associated with pre-pregnancy folic acid. It may also be the case that confounders are more strongly associated with pre-pregnancy folic acid than functional health literacy. Alternatively it may be that functional health literacy is only weakly associated with pre-pregnancy folic acid and confounders such as income are driving this association. There is a need for studies in larger samples to clarify the relationship between functional health literacy and confounders with pre-pregnancy folic acid.

Breast feeding was initiated by more women in the adequate functional health literacy subgroup (72.5%) compared with the limited functional health literacy subgroup (60.6%) but this difference did not reach statistical

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significance ( $p=0.09$ ). Regression analysis testing for confounders did not change this finding as the odds ratio did not reach statistical significance.

GDM was diagnosed in 16.7% of those with limited functional health literacy compared with in only 6.2% of those with adequate functional health literacy. The difference did not reach statistical significance ( $p=0.06$ ), which may reflect that there is no difference or that the sample size was insufficient to detect a statistically significant difference, if present. Regression analysis did not reveal a significant association following adjustment for confounders, which can be interpreted as the result from the raw data as unchanged. There were no significant association between functional health literacy and gestational hypertension, pre-eclampsia, Caesarean section delivery and a composite of adverse maternal outcomes. After adjustment for confounders (income, education and parental ethnic background) there was a significantly lower odds ratio for pre-eclampsia only. As the number of cases of pre-eclampsia was small ( $n=4$ ) it is not possible to interpret this finding.

Adverse neonatal outcomes were not significantly associated with functional health literacy and these findings did not change after adjustment for confounders. A similar analysis of general health literacy with pregnancy-related factors and adverse pregnancy outcomes did not reveal any significant associations.

#### **4.2 Study sample socio-demographic characteristics**

##### *Age, Ethnic background, marital status*

In our sample the mean age was 33.9 years, which is older than the national average of mothers registered at maternity services, of 32.7 years (2016, first quarter) as reported by the Central Statistics Office (CSO) on births in the Republic of Ireland (154). A total of 16,480 births were registered in the first quarter of 2016, of which 78.2% were to mothers of Irish nationality and 6.5% were to mothers whose nationality was non-EU. Our sample of pregnant women had a similar ethnic composition, with 74.3% of participants stating that both of their parents were Irish and 6.8% stating that both of their parents were born outside of the EU. However those participants whose parents were born outside of the EU may themselves have been born in Ireland and/or were educated in Ireland and so a smaller percentage than the national average were likely to have been born outside of Ireland and the EU. The first quarter results, 2016, from the CSO report that 36.6% of all births in Ireland were to mothers who were single (not married/not in a civil partnership) (154). In my study this was lower at 26.3%, with almost three quarters (73.6%) stating they were married.

##### *Educational status*

The Central Statistics Office's latest report on education status in Ireland (2013) reported that 55.3% of women between 25 and 34 years had achieved a third level qualification (155). In my sample this was higher, at 76.5%, indicating that the education attainment was higher in this group than in the national average.

##### *Employment*

The HSE Crisis Pregnancy Programme and the Equality Authority of Ireland commissioned a report on pregnancy and employment in Ireland and this was published in 2011 (156). The review reports a trend of increasing rates

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of employment of women over the 10 year period from 1997 to 2009. In 2009, the final year included in the report, three quarters of all women in childbearing age (22 to 44 years) and 60% of mothers of pre-school children were in employment in Ireland. A more recent report by the Irish Business and Employers' Confederation (IBEC) on women working in Ireland reports a similar percentage of mothers with children under 5 years in employment (55.6%) and 85.6% of women with no children in employment (157). The percentage of the pregnant women in my study who were in employment was high at 82.2%. Thirty four point four percent were expecting their first child. Overall it is likely that more of the pregnant women in my study were in employment compared to the national average of women of childbearing age in Ireland.

### *Smoking*

The Growing up in Ireland, maternal health behaviours and child growth in infancy reported that 17.6% of the 11,134 mothers who participated in the study smoked at some stage during their pregnancy and 12.6% smoked during all three trimesters of pregnancy (158). This refers to pregnancies between December 2007 and May 2008. There is a trend of reduction in smoking during pregnancy; for example the report compares the rate in 2007/2008 to that of a previous report where the rate of smoking in pregnancy was 28.1%. In my sample only 4.1% were smokers, which may be either lower than the national average and/or reflects the continuing trend of lower numbers of women smoking during pregnancy.

### *Exercise*

The HSE in collaboration with the Institute of Obstetricians and Gynaecologists (Royal College of Physicians of Ireland) published a clinical practice guideline in 2011 (updated 2013) on obesity and pregnancy (159). This report concurs with the report from the American College of Obstetrics and Gynaecology, which recommends regular exercise, both aerobic and strength-conditioning exercises throughout pregnancy for

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women with uncomplicated pregnancies (160). There is little data available on levels of exercise during pregnancy. In my study only 35.7% exercised daily or a few times a week, which leaves 64.3% who did not meet the above recommendations.

### *BMI*

Data from the ATLANTIC DIP study, which is a prospective observational study, across 5 obstetrical service centres in the West of Ireland, including University Hospital Galway, reported booking BMI in 3,929 pregnant women as normal, overweight and obese in 42%, 37% and 21% respectively in a cohort of pregnant women with normoglycaemia (132). A study conducted in 2008-2009 in a Dublin hospital found rates of normal BMI, overweight and obesity in 1,200 pregnant women in attendance at 51.75%, 27.4% and 18.1% (161). In my study the rates of normal BMI, overweight and obesity were 53.8%, 29.2% and 17% respectively; these rates are similar to the data from the Dublin hospital study.

### *Income*

Overall incomes were higher in my study sample compared with incomes in the 1005 participants from Ireland in the EU HLS, data collected in 2011. For example, 46% of my sample had a monthly net income of €3,600 or higher compared with only 13.6% in the Irish sample from the EU HLS. The CSO reports that the ‘at risk poverty threshold’ in 2014 was a disposable income of €10,786 and that 16.3% of the population were at risk (162). In my sample 11% had a monthly disposable (net) income of €1,350 or less, indicating that the ‘at risk of poverty’ was less than 11%.

### *Self-rated social status*

The population European HLS included 1005 participants from Ireland, with mean age 45 years, ranging from 15 to 91 years (21). In the Irish sample 13.9% perceived their social status as high or very high. In my study, the

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mean age was 33.9 years and ranged from 19 to 49 years; 17.2% perceived their social status as high or very high. This is higher than the population data from the HLS and, conversely, while the HLS data reported that 15.3% perceived their social status as low or very low, only 3.8% of my sample rated their social status at this level.

### *Perceived health*

The latest report on health trends in Ireland was published in 2015 and this reports, in 2013, that 89.8% of women between 25 and 44 years perceive their health as good or very good (163). In my study the percentage of participants who rated their health as good or very good was even higher at 94.2%. Ireland has the highest percentage of its population (aged 16 years and older) who rate their health as good or very good in the EU.

In summary comparison of the pregnant women in my study with pregnant women attending maternity services in Ireland reveal that my sample were older (mean age 33.9 versus 32.7 years nationally), a higher percentage were in a long-term relationship (73.6% versus 63.4% nationally), more had achieved a higher education level (76.5% versus 55.3% nationally in a similar age group) and more were in employment compared to the national employment rate of women of child bearing age. Monthly household incomes were higher and fewer were at risk of poverty than the national average. Self-perceived social status, a measure of socio-economic status, was higher in my sample with more rating their social status as high and less rating their social status as low compared with the Irish population sample in the EU-HLS. A very high percentage of my sample rated their health as good or very good (94.2%) which is higher than reported nationally. Only 4.1% were current smokers, which is low compared with available data on smoking in pregnancy nationally.

Overall participants in my study were more educated, earned more, had a higher social status and were healthier than pregnant women in the region and at a national level. It is likely that exclusion criteria for this study and

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the screening criteria for risk of GDM contributed to the socio-economic profile of my sample. For example pregnant women who had difficulty understanding written and/or spoken English were excluded. This exclusion criterion means that pregnant women from overseas and who may have had lower educational attainment were likely to be excluded and women whose native tongue is English were more likely to be recruited. This also led to a higher percentage of participants, whose both parents were Irish, being recruited. The educational system in Ireland is such that a high percentage of girls complete secondary level, for example ninety two percent of girls who started secondary school in 2008 sat the leaving certificate examinations in 2013/2014. Ireland is ranked eighth in the 28 EU member states in second level education completion rate. Also, as noted, those participants whose parents were born outside of Ireland, may have themselves grown up in Ireland and this is also contributing to the high level of post-secondary and third level educational attainment. Galway city and county has 2 maternity services; one in University Hospital Galway where I recruited my participants and which serves the city and surrounding area, and therefore a more urban population, and Portiuncula University Hospital which serves a more rural population. This may have also influenced the socio-demographic profile of my sample as living in or near a city which has a university and a third level institute of technology, likely contribute to a high uptake of third level education. Those who live in more rural and disadvantaged areas have lower rates of completion of second level education and attendance at third level institutions. These factors likely contributed to the observed differences in my sample compared with the socio-economic profile of pregnant women in Ireland.

### *Issues of biases*

#### *Selection bias*

My population of interest is women at increased risk of GDM. The recruitment process was limited to those who (a) were referred for an OGTT and (b) those who turned up to the department for this test, over the

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recruitment period. There is a possibility of selection bias here as it may be the case that not all women at risk of GDM are referred for an OGTT and secondly some of those referred may not attend for an OGTT. This may have a negative impact on the generalisability of my findings. Some studies on health literacy in pregnancy suggests that those with limited health literacy may be late at attending antenatal care, and have fewer antenatal visits during pregnancy (101-103). Uptake of other health screenings, such as breast cancer screening, was found to be significantly associated with health literacy, with uptake lower in those with low health literacy (164). This may also be the case in my study, which studied women referred for GDM screening, which could mean that, of those, who do not attend for GDM screening, a higher percentage may have limited literacy compared with those who do attend. On the other hand, it is also apparent that selection bias is less of a problem in my study design (a cohort study) where the outcomes of interest are not known at the time of data collection, than, for example, in a case control study.

### *Information bias*

Information bias is another source of bias in clinical research studies. The data entered from data collection is only as good as the accuracy of which the data represents the true information on the participants. In my study my data was obtained from self-completion of a questionnaire on socio-demographic details of participants or data sourced from electronic databases (clinical and laboratory). While completion of demographic details by participants is likely to more accurate than collection of such data from clinical files, there is still the possibility of inaccurate information collection. This can occur if participants misinterpret one or more items in the questionnaire during completion.

As detailed in the methods section, the 2 health literacy measures were administered at the time of attendance for the OGTT. The measures were administered by the study author and a research assistant. Efforts were made to minimise risk of information bias by (a) prior both the author and

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research assistant being blinded to the socio-demographic characteristics of participants, with the exception of those who were likely to be from ethnic minorities (which was unavoidable at time of interview) and (b) by standardisation of administration of health literacy measures. This included a discussion on the instructions from the health literacy measure authors (NVS (U.K.) and EU HLS-Q) and administration of both measures under similar conditions, by the researchers in advance of study data collection. The EU HLS-Q is a self-reporting measure of likely ease or difficulty in performing health-related tasks, many of which the participant may have experienced in real life. This can introduce recall bias and the participant can under-report or over-report either ease or difficulty in performing the health-related tasks in the questionnaire. Similarly participants can over-estimate or under-estimate ease or difficulty in performing those tasks in the questionnaire which they have not experienced. This is termed self-report bias and can lead to error in categorising participants in the wrong health literacy category of the EU HLS-Q.

Retrieval of information from participants' electronic records was conducted by an assistant researcher, who has many years of experience in accessing, navigating and retrieving clinical information from the maternal database and laboratory database for results of OGTT tests. This is expected to reduce the error in collecting of data from these sources, as a research assistant with little or no knowledge or experience of these databases would be at higher risk of retrieval bias/error. At the time of collection of clinical and laboratory data the research assistant was blinded as to the health literacy results of participants. Despite these precautions there is always a residual risk of missing data, inaccuracies in data recorded and retrieval bias.

### *Confounding bias*

Confounding bias can be explained as a "distortion of the association between an exposure and an outcome that occurs when the study groups differ with regard to other factors that influence the outcome" (165). This

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means that an inaccuracy can be introduced in the estimated measure of association that occurs when the measured factor of interest is mixed up with some other factor(s) that are associated with the outcome. In health literacy there are a number of confounding factors such as age, education, income, employment and ethnicity. From research in health literacy, as summarised in the introduction section, these factors increase risk of both limited health literacy and adverse health outcomes i.e. they are confounders. This is supported by studies, which report unadjusted findings of significant associations between limited health literacy and health outcomes, but when adjusted for a number of confounders these associations are no longer significant. On the other hand, there are a number of health outcomes which have been shown to have significant associations with health literacy, even after adjustment for confounders. For example the authors of the updated systematic review on health literacy and health outcomes conclude that there is moderate strength of evidence (defined as having “moderate confidence that the evidence reflects the true effect”) that low health literacy is associated with higher rates of hospitalisations, emergency service utilisation, breast cancer screening uptake and influenza vaccination (164). These associations are reported following adjustment for confounders. In the case of other health outcomes the evidence is low or insufficient due to low number of studies, lack of adjustment for confounders, small number of participants and/or poor methodology. In pregnancy, adverse outcomes are associated with lower education, ethnic minorities, lower incomes, and unemployment and there is some evidence that it may be associated with limited health literacy. The number of studies on health literacy in pregnancy is small to date and the strength of evidence linking health literacy to adverse pregnancy outcomes is likely to be low/insufficient. My results confirm that, a number of these risk factors known to be associated with adverse pregnancy outcomes, are associated with low functional health literacy. These include ethnicity, education attainment, employment and income. Ethnicity, income and education also predicted functional health literacy.

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These factors are confounders, as we know they are also associated with health outcomes. From my results it is unclear if health literacy is independently associated with pregnancy-related factors or adverse pregnancy outcomes in women at risk of GDM: the results may reflect no associations where no association exists or there may be inadequate numbers of participants with adverse pregnancy outcomes to detect significant associations. Further studies in pregnant women at increased risk of adverse pregnancy outcomes, may confirm that health literacy is significantly associated with adverse outcomes; multivariate analysis of results will determine if associations found are independent of confounders.

#### **4.3 Incidence of adverse pregnancy outcomes**

There were 30 cases of GDM (10.3%) and 17 cases of gestational hypertension (6%) in my sample. The ATLANTIC DIP collaborators conducted universal screening for GDM between 2006 and 2009, using the IADPSG criteria, which are the same diagnostic criteria used in my study (118). Universal screening of 5,500 pregnant women yielded a rate of GDM of 12.4%. The response rate in the ATLANTIC DIP study was 74.1%, with a completion rate of 44.1%. Those who did not complete the study had a lower BMI and were younger than those who did participate, which may explain, in part, the higher GDM rate found in the study, compared to my data. In addition the ATLANTIC DIP was a universal screening programme and it has been shown that selective screening programmes can omit between 5% and 20% of pregnant women who develop GDM, depending on the screening guideline applied (166). By comparison, the rate of GDM in my study is higher than reported in the National Maternity Hospital in 2015 at 4.1% and the annual report from University Hospital Galway in 2014 at 6.4% (119, 120). It is not surprising that the incidence was higher in my sample, as participants in my study were, by definition, at increased risk of developing GDM.

In the 2014 University Hospital Galway maternity annual clinical report shoulder dystocia was reported in 25 cases (0.9%), congenital abnormalities were diagnosed in 42 cases (1.4%) and macrosomia was reported in 16.3% of births. Overall adverse neonatal outcomes occurred less frequently in my sample of pregnant women, with no cases of shoulder dystocia or neonatal hypoglycaemia, 1 case of congenital abnormality (0.3%) and a similar rate of macrosomia at 16.1%. In my study preterm delivery occurred in 5.2%, compared with 6.5% in the 2014 annual report from University Hospital Galway. Admission to the neonatal intensive care unit (NICU) was reported at 13.4% in the 2014 annual report; this was lower at 4.2% in my sample. The University Hospital Galway annual report 2014 includes cases of multiple pregnancies (twins, triplets), which

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occurred in 2.5% of cases; I did not include multiple pregnancies in my pregnancy outcomes analysis and this may explain, in part, the higher rate of NICU admissions in the hospital annual report. Caesarean section and assisted vaginal delivery rates in my study were similar to those reported nationally while antenatal complications, with the exception of GDM, occurred less frequently in my sample. To summarize, my participants were more educated, earned more, had a higher social status, had higher self-rated health and had less adverse pregnancy outcomes (excluding GDM) than reported in pregnant women regionally and nationally.

#### **4.4 Interpretation of Health Literacy findings**

##### *Newest Vital Sign results*

There was a lower percentage of limited functional health literacy in my sample compared with the population sample from Ireland in the EU HLS; 42.4% had limited functional health literacy (comprised of 19.9% with a high likelihood of, and 22.5% with a possibility of, limited functional literacy) compared with 25.3% (comprised of 2.7% having a high likelihood and 22.6% a possibility of limited functional health literacy) in my sample. The higher frequency of limited functional literacy may be partly explained by the older age group, lower education attainment and lower perceived social status and the inclusion of both male and female participants in the Irish population study. There are to date no other reported studies on functional health literacy in pregnant women in an Irish setting. In the U.S. Bennett et al. reported that 16% of a sample of 202 pregnant African American women attending had low functional health literacy, as measured by the REALM. Moynihan reported that 56.4% of women who had delivered preterm infants (sample size was low with n=56) had inadequate functional health literacy, as measured using the REALM, in a study in the U.S. state of Georgia (105). Ehrenthal measured functional health literacy, after delivery and prior to hospital discharge, in 249 women whose pregnancies were complicated by GDM, in a single centre in the U.S. (106). Functional health literacy was measured using the REALM (short form) and they report limited literacy in 8.9% of the sample. The REALM is a word recognition test, which unlike the NVS does not test comprehension and numeracy literacy. One study which compared these 2 measures of functional health literacy found that 15% of patients who achieved adequate functional health literacy with the REALM, had a possibility of limited literacy according to their NVS score (167). Endres et al. measured functional health literacy, using the S-TOFHLA, in pregnant women with diabetes attending antenatal clinics (104). They reported that 22% (sample size 74) had low functional health literacy, using a cut-off of 30 or less. This

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threshold varies from the threshold established by the authors of the S-TOFHLA of 22 or less for low functional health literacy.

Direct comparison of levels of functional health literacy in these studies and the findings of my studies are difficult to make, due to the different measures used and the differing percentages of limited functional literacy with these tools: Kiechle et al. compared 6 measures of functional literacy, which included the NVS, the S-TOPHLA and the REALM-R and found that the S-TOFHLA categorised the lowest percentage (7.5%) and the NVS the highest percentage (48%) as having limited functional health literacy (48). Also the sample sizes are small, less than 100 in some of the studies, and these prevalence data may not be confirmed in larger samples.

### *EU HLS-Q results*

In the population EU HLS data from Ireland, 10.3% had inadequate and 29.7% had problematic general health literacy; the authors described the combination of these 2 categories as limited health literacy, which means that 40% had limited health literacy (21). This is similar to the finding in our study, where 38% had limited health literacy. The data from Ireland reported 38.7% had sufficient health literacy, in my study this was higher; 49% had sufficient health literacy. There was a higher percentage with excellent health literacy in the Irish sample in the EU-HLS (21.3%), compared with 13% in my study. However the percentage with adequate health literacy was similar in both groups; 63% in my sample and 60% in the population sample from Ireland.

Similar to my findings, results from the population data from Ireland reports that the highest percentage of sufficient or excellent health literacy was in HC-HL index and the lowest percentage was in HP-HL index, at 75.5% and 56.31% respectively. DP-HL index was positioned between the 2 other sub-indices, with 62.93% having sufficient or excellent literacy in this index.

*Items of note*

*HC-HL index*

In general tasks that involve following medical instructions or finding where to get health information were rated as easier to do than tasks where judgement on quality and source of health information was required. In my study 54.7% rated as difficult or very difficult the task of judging when they may need to get a second opinion from another doctor compared with 36% in the EU HLS data from Ireland. Judging how reliable “information about illness in the media is” was rated as difficult or very difficult by two thirds of participants (66.8%) in my sample, while the EU HLS data from Ireland reports that 43.7% rated this task as difficult or very difficult. In my sample 37.8% of participants rated judging the advantages and disadvantages of different treatment options as difficult or very difficult, which is similar to the population data from Ireland, where 36% rated this task as difficult or very difficult. Similar percentage of the Irish population sample in the EU HLS and in my sample found it difficult to understand the leaflets that come with medications, namely approximately 1 in 5. Lack of ability to understand medication leaflets can lead to misinterpreting instructions, which has been shown to be linked to low functional health literacy (59). The significance of 20% of this patient population having difficulty in understanding medication leaflets is augmented by the fact that pregnant mothers follow instructions on medications, not only for themselves and their unborn babies, but frequently for other dependents/children in the family. This result must also be viewed in the light of current EU legislation which requires the pharmaceutical industry to design information leaflets in consultation with target patient groups (168). If 20% of the population have difficulty understanding leaflets with medications then it is likely that this is not taking place universally or that the process does not adapt medication leaflets in response to concerns from those with limited literacy.

*DP-HL index*

Very few pregnant women rated how to find information on how to manage unhealthy behaviour as fairly or very difficult (2.7%); however 28.2% rated how to find information on how to manage mental health problems as fairly or very difficult. In the EU survey 31.2% of the Irish sample rated this as fairly or very difficult. This may reflect the fact that efforts to promote mental health and increase awareness of mental health issues have gained momentum in recent years only, compared with public health campaigns promoting other areas of public health. Key policies and publications in recent years in this field are the Mental Health Action Plan for Europe (2005) and the Irish policy documents 'A vision for Change, 2006' and 'Reach Out, 2005' (169).

Forty two percent of pregnant women found it difficult to decide whether they should have the flu vaccine. The HSE website explains the flu vaccine recommendation for pregnant women, including risks and benefits (170). There is also an annual campaign to promote information and uptake on the seasonal flu vaccine for at risk groups, which includes pregnant women. In spite of these measures 2 in every 5 pregnant women in my study found it difficult or very difficult to decide if they should have the flu vaccine. To address this difficulty public health groups will need to explore the values and beliefs of pregnant women, health knowledge, cultural and social conditions, which are contributing to this difficulty. It is likely that provision of information alone, will not address this difficulty.

Similar to the question on judging 'how reliable information about illness in the media is' in the HC-HL index, a high percentage, namely 58.5% of participants found it difficult or very difficult to judge how reliable information in the media is on health risks. In the EU HLS, data from Ireland 36.5% of participants rated this as fairly or very difficult.

These results demonstrate that 1 in 2 pregnant women are not sure if sources of information in the media on health and health-related matters

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are reliable. This could be due to poor skills in recognising the nature of the information posted in the media; for example this could be a patient story and his/her experience, an opinion, a report on medical research, an advertisement or a reader's response to a previous piece of writing. A reader can also have difficulty in recognising the source of the information in the media; for example is the report given by someone who has read or experienced the content of the piece of writing and has the skills to accurately report the findings? Is there any possibility of bias in the reporting e.g. reporter has an affiliation with a party who stands to benefit from a particular interpretation of the facts? A poor ability to understand and make decisions on the evidence being presented could also lead to difficulty deciding if information in the media is reliable. Finally poor ability to decide if the evidence presented is sufficient to reach the conclusions given may lead to difficulty in judging how reliable information is in the media. If there is poor ability in one or more of these processes then this can account for difficulty in judging the reliability of information in the media.

### *HP-HL index*

More than half of the participants (58.8%) rated as fairly or very difficult to 'find information on how their neighbourhood could be more health friendly'. This is higher than the Irish population sample in the EU HLS, where 37.2% found it fairly or very difficult (21). In my study 65% found it fairly or very difficult to 'find out about political changes that may affect health', compared with 43.6% in the Irish population study. The proportion of participants who indicated that both parents were born in Ireland was lower in my study, at 74.3%, compared with 91.7% in the Irish population sample of the EU HLS, which may, in part, contribute to the difference between the 2 groups on this item. Difficulty understanding information on food packaging was an issue for 1 in 3 participants, similar to the finding in the Irish population study. This is despite an EU directive on the provision

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of food information to consumers which states “food labels should be clear and understandable in order to assist consumers who want to make better-informed food and dietary choices” (171).

#### **4.5 Health Literacy and socio-demographic factors**

##### *Functional Health Literacy*

Those with a third level education had a higher median NVS score compared with those who left formal education at lower secondary or primary level. This is not surprising as there are numerous population studies which report an association between health literacy and education attainment. For example in the U.K. von Wagner et al., measured functional health literacy using the TOFHLA and found the risk of having limited health literacy was associated with low educational attainment (56). This association was also found by Adams et al., in an Australian population sample (n=2,824), where the authors measured functional health literacy using the NVS (54). The European HLS found a significant association between NVS score and education attainment (21).

My results found that functional health literacy was significantly lower in the unemployed and student/on work experience groups, and highest in those who were in full-time employment or self-employed. Similarly pregnant women on the lower income levels had lower functional health literacy compared to those on the higher income levels. These findings are in agreement with findings in population studies on functional health literacy, such as the Adams study in Australia, which employed the NVS and the von Wagner study in the U.K. which used the TOFHLA to measure functional health literacy (54, 56).

Participants whose parental ethnic background was non-Irish had lower functional health literacy compared to the women who had one or both parents who were Irish. The differences across groups were statistically significant. Functional health literacy in the Australian population study, as measured by the NVS, found lower functional health literacy in adults who were born outside of Australia, New Zealand, England and Ireland,

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reflecting the increased risk of limited functional literacy in adults from other ethnic backgrounds (54). In the U.K. Rowlands et al. reported lower text literacy and numeracy literacy, in the healthcare setting, in those for whom English was not the first language (55).

My results found significantly lower NVS scores in current smokers compared with former smokers and non-smokers. The population study in the U.K by von Wagner et al. and a community based study of health insurance enrollees in the U.S. explored smoking status and functional health literacy: the authors measured functional health literacy using a modified TOFHLA and the STOFHLA respectively (56, 68). Findings from these 2 studies are conflicting. The U.K. study reported a “higher health literacy was associated with a small increased likelihood of not smoking” while the U.S. study found no difference in smoking status in those with adequate, marginal and inadequate health literacy.

My results found higher NVS scores in those with private health insurance and lower scores in those with public only or no health insurance. A U.S. study reported a significant association between parental low health literacy and children more likely to be without health insurance (5). Morris et al. conducted a study in 1,002 patients with a diagnosis of diabetes in primary care in the U.S. and found a significant associations between functional health literacy, as measured by the STOFHLA, and health insurance status (73).

The EU HLS-data from Ireland reported that the NVS score was significantly correlated with self-reported social status, reporting lower functional health literacy in those who rated their social status as low or very low (21). This is in agreement with my results which found statistically significant differences between the subgroups of low, middle or high self-rated social status.

I found no difference in NVS scores between pregnant women who exercised frequently, infrequently or not at all. In their study von Wagner

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et al. measured functional health literacy using a modified TOFHLA and did not find health literacy to be associated with "having exercised in the last week" (56). In the U.S. study of elderly medicare enrollees lower functional health literacy was more common in those who exercised infrequently (71). Half of my participants did not exercise regularly; the reasons for this are not apparent but lack of knowledge of guidelines on exercise during pregnancy and busy work and home lives may be contributing factors.

Levels of functional health literacy were not significantly different across the 3 BMI categories of normal BMI, overweight and obese. The systematic review of functional health literacy measures by Berkman et al. reported on a small number of studies on BMI and concluded that the strength of evidence on the relationship between BMI and functional health literacy as "inconclusive" (164). None of the studies were conducted in either pregnant women or in the women of child-bearing age group.

I did not find an association between self-rated health and functional health literacy. As mentioned above the percentage of pregnant women rating their health as good or very good was very high at 94.2%. Berkman et al. reported the evidence of lower health literacy associated with lower self-reported health status as "moderate" (5). For example, one study by Cho et al., reported higher health literacy was associated with higher health status; functional health literacy was measured with the S-TOFHLA and the sample was 489 elderly Medicare patients in the U.S. (58). Conversely Baker et al. reported no significant association between functional health literacy level and health status in 3,260 New Prudential Medicare enrollees in the U.S. (55).

Finally there were significant differences in functional health literacy status across income categories. This is in agreement with population studies on functional health literacy which found higher prevalence of inadequate functional health literacy in those on lower incomes (52, 53).

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This analysis included 10 demographic characteristics and two measures of health literacy and the issue of multiple comparisons arises in the interpretation of the findings of statistically significant associations in the results. Multiple comparisons increase the likelihood that the observed differences have occurred due to the play of chance. This can be interpreted as the more factors included in an analysis the greater the chance of finding one or more factors to be significantly associated with the outcome in question, even when no association exists. For example, in the case of 20 variables there is a 1 in 20 chance of finding a significant association, which can mean that p value of <0.05 would be inappropriate and that a p value of <0.001 may be more suitable to detect a significant difference between a variable and a measured outcome, if one exists. This will help in avoiding what is termed a type 1 error in statistics: that is where there is a false conclusion that an observed difference is real when no difference exists. In my study where I tested 10 demographic characteristics for associations with limited health literacy I can conclude that those variables with the lowest p values have the strongest associations with functional health literacy. As detailed in table 3.10 (page 115) there were significant between group differences in functional health literacy status (limited and adequate) in the demographic variables of parental ethnic background, health insurance status and monthly household income with a p value of <0.001; these findings can be interpreted as robust and not influenced by chance. At the same time the finding of between group differences in smoking status with a p value of 0.02 can be interpreted more cautiously in the light of the multiple variables tested.

### *General Health Literacy (EU HLS)*

My results on general health literacy, as measured by the GEN HL index, found statistically significant differences between groups in parental ethnic background and self-rated health status. Participants who had one or both

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parents born outside of Ireland had higher mean scores than those who had one or both parents born in Ireland. This finding is in contrast to the functional health literacy results, which found lower NVS scores in those whose parents were born outside of Ireland. The EU HLS data did not find a significant association between parental ethnic background and general health literacy (50). Participants who rated their health as high had higher general health literacy, compared to those who rated their health as low.

I did not find a trend between education attainment and general health literacy. In the EU HLS, data from Ireland, there was a progressively higher mean general health literacy scores as levels of education attainment increased (21). Differences were significant between the groups. Differences between my sample and that of the Irish sample in the EU HLS were age, gender and a higher proportion of those with third level education. My sample was also smaller and may not have been sufficient to detect significant differences, if present.

Self-rated social status, is a subjective indicator for socio-economic status; my results found those who rated their social status as high had the highest mean score in the GEN HL index, while those who rated their social status as low had the lowest mean score. Differences across the 3 levels of self-rated social status i.e. low, middle and high did not reach statistical significance. The EU HLS, data from Ireland, found a similar progression in general health literacy across social levels, with the differences across groups reaching statistical significance (21).

My finding of a significantly positive association of self-rated health with general health literacy has been found in population health literacy studies. A study from a U.S. population sample ( $n= 2,668$ ) found a positive association between health literacy level and self-reported health status (172). Findings from a population sample in Canada also found that health literacy was positively associated with self-reported health status (173). In contrast the EU HLS, data from Ireland, found that general health literacy was inversely associated with self-rated health (21). The Canadian data is

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from the adult literacy and skills survey and the U.S. study from the National Adult Literacy Survey, where items are direct testing of literacy skills, which is in contrast to the HLS, where the individual self-reports his/her literacy skills. This may explain some of the contrasting findings in these studies. Delaney et al. reported that education and income are positively related to self-reported health in a population Irish sample from the European social survey (174). Health literacy, however, was not included in this analysis.

### *Summary of sociodemographic factors and general health literacy levels*

The U.S., Canadian and Australian population based studies of general health literacy conducted in the 2003, 2003 and 2006 respectively found significant association between lower health literacy and those who were unemployed (Canadian and Australian studies), had a lower level of education (U.S. and Australian studies), immigrants from a non-English speaking country (all 3 studies), older adults (all 3 studies), male participants (U.S. study), low self-reported health status (U.S. study) and adults living below the poverty line (U.S. study) (4, 52, 53). In my results I found statistically significant between groups differences in general health literacy in parental ethnic background and self-rated health status, and trends, which were not statistically significant, in income levels and social status.

The National Assessment of Adult Literacy (NAAL) in the U.S. contained a health literacy component which was a task-based assessment in the domains of health care and health information in clinical, preventive and navigation of the health system (4). Similarly the Australian Adult Literacy and Life skills Survey (ALLS) and the Canadian International Adult Literacy Survey (IALS) ask the participant to complete tasks relating to health in broadly similar domains (52, 53). These general health measures therefore, share similarities with the EU HLS in terms of the domains and processes

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measured; however, there is a difference in how literacy is measured, as the U.S., Canadian and Australian surveys ask the participant to complete tasks, while the EU HLS asks the participant to self-report his/her likely difficult in performing tasks related to health (51). By comparison my sample was from a population of pregnant women at risk of GDM and employed a self-reporting measure of health literacy (EU-HLS). These factors, and the possibility of my sample size being too small to detect statistically significant differences in socio-demographic associations of general health literacy likely contribute to my findings.

### *Predictors of Health Literacy*

My results found that household income and education positively predicted functional health literacy. By comparison parental ethnic background negatively predicted functional health literacy. Social status and parental ethnic background positively predicted general health literacy. In the EU HLS, data from Ireland, social status and income positively predicted general health literacy, and parental ethnic background was not a predictor (18). Predictors of functional health literacy are not reported in the EU-HLS report. These variables have been identified in population based studies as risk factors for low health literacy (4, 49, 50, 53). The finding that non-EU parental ethnic background positively predicted general health literacy may reflect the nature of the EU-HLS, being a self-reported measure of health-related tasks. Functional health literacy, by comparison, which is a direct test of literacy, found that non-EU parental ethnic background negatively predicted functional health literacy level. This is in agreement with the population based studies which found that immigrants and ethnic minorities negatively predicted functional health literacy.

The conceptual model by Paasche and Wolf (figure 1.2, page 38) linking health literacy to health outcomes includes a number of factors which are associated with health literacy; these include ethnicity, education and

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income, which I found were predictors of functional health literacy in my results. The model includes a number of other factors associated with health literacy; this may, in part, explain the finding that the variables I included in my multiple regressions explain only 20.3% of the variance in functional health literacy and 5.4% of the variance in general health literacy. The EU HLS, data from Ireland, reported that confounders entered in their regression analysis accounted for 7.2% of the variance in general health literacy, with only income and social status reaching statistical significance ( $p<0.05$ ). The other variables entered in their regression analysis were age, gender, education and parental ethnic background. Other factors which are linked to health literacy that Paasche and Wolf include in their conceptual model are occupation, employment, social support, culture, language, health status (vision, hearing) and cognitive skills (verbal ability, memory and reasoning). Factors that may play a role in health literacy in my sample and which I did not measure are likely to include some of these factors in Paasche and Wolf's model (social support, occupation, language). Other additional factors in this cohort that could influence health literacy are attendance at community-based activities, for example attendance at the gym, weight-reduction classes, exercise classes, public seminars on diet and health living; participation in self-help groups, caring roles for dependents (children, the elderly, those with disabilities), previous interactions with health care systems and informal self-education activities such as reading and/or listening to health information in the media, participation in conversations and debates on health. The definition of health literacy by Baker explicitly refers to health literacy as being "dynamic" i.e. changing over one's life course and includes health knowledge (34). It is likely that health knowledge, which can be delivered in formal education, by Government departments (Department of Health, Public Health agencies), by the health services and through media campaigns and general media communications, can also influences health literacy in pregnant women. In particular in my study where the majority of participants were highly educated, had comparatively high incomes and a

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high social status they were likely to be well informed and have a relatively good health information and knowledge relevant to their and their families health. Health knowledge would likely influence health literacy, therefore, in my sample of pregnant women.

#### **4.6 Identifying individuals with limited health literacy**

*Identifying individuals with limited health literacy using risk factors such as education or income as a proxy for health literacy*

Population studies and studies in diverse patient groups confirm that there are a number of common risk factors that increase likelihood of limited health literacy. As discussed in the introduction these include age, ethnicity, education attainment, income, self-rated health, self-rated social status and employment status. I have confirmed in my study that a number of these are significantly associated with risk of limited functional health literacy. This observation raises the question if persons with limited health literacy can be identified by their risk factor profile, negating the need to employ a health literacy measure, to identify those at risk of low health literacy. This could be an attractive proposal as it would allow easy and quick estimation of health literacy status, without the need to administer a health literacy measure, and would be beneficial in identifying patients likely to be at risk in busy clinical settings, allowing appropriate tailoring of health service communication and delivery.

To address this proposal, the first issue I want to highlight is that there is some evidence that physicians and other healthcare professionals have low level of knowledge of health literacy and frequently overestimate patients' health literacy. Studies confirm that there is a lack of awareness of health literacy among health care professionals and misconceptions about what health literacy is, among those who were aware of health literacy (175, 176). In the U.S. 2 studies found that physicians inaccurately rated patients' literacy levels in 34% and 39% of participating patients and that overestimation of health literacy occurred in 32% and 25% of participants respectively (177, 178). Overestimation can lead to a mismatch between the patient's ability to comprehend information and concepts and the level of complexity used by the physician when communicating with the patient.

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It could be proposed that these issues could be addressed by education programmes for healthcare professionals on health literacy and, in particular, risk factors of low health literacy. It could be argued that identification of an individual's level of formal education, ethnic background, or income level could provide sufficient information to make a judgement of his/her health literacy level. This proposal can be considered by (a) observation of the socio-demographic characteristics of those with low health literacy from population studies and (b) the performance of risk factors as predictors of low health literacy and (c) change/improvement when a health literacy measure is added to one or more risk factor.

From the International Adult Literacy Skills survey (2003), results from Canada, low health literacy was more prevalent in older Canadians, immigrants and the unemployed (52). However in each of these at risk groups there was a significant percentage with adequate health literacy. In addition, there are significant percentages in those aged less than 65 years, non-immigrants and in the employed who have limited health literacy. In the NAAL study in the US (2003) 40% of those who had completed a high school education had low health literacy (4). If education was used to predict those with limited health literacy 40% of those with a high school education would be mislabelled as having adequate health literacy. Van der Heide et al. analysed data from the Dutch population study using the NALS (2003) and found that 32.3% of those with third level education and 53.5% of those with upper secondary education had inadequate health literacy (179).

If education were used as a proxy health literacy would be overestimated in these individuals. My results show similar findings with 22.3% and 37.9% of those with third level and upper secondary level education respectively had limited functional health literacy; limited general health literacy was found in 38.6% of those with third level and upper secondary level education. This is supported further by a study on numerical literacy in a population sample (n= 463), the majority of whom had completed a high

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school education, which reported that approximately 20% answered the easiest items incorrectly (180). Similarly a U.S. study in African American patients with cardiovascular disease reported only moderate correlation of years in education and literacy scores in a word recognition and pronunciation test (Spearman's rank order correlation 0.55,  $p<0.0001$ ) (181). Similarly Gazmararian et al. and others report a significant percentage of those with high school completion or higher have limited functional health literacy (42, 182). These findings support the argument that achievement of a minimum level of formal education alone may not be sufficient to estimate health literacy.

Income is also linked to health literacy, as detailed in the introductory section on population studies and confirmed in my results. There are difficulties using income as a proxy for health literacy as income is reported in a number of different ways, which can alter the relation of an income bracket to level of affluence and/or relation to poverty thresholds and is expressed in varying currencies, making comparisons difficult. For example, income can be expressed as gross income, net income, individual income, household income, monthly income, yearly income. Nevertheless there is a gradient across income brackets in terms of health literacy, with limited health literacy more prevalent in those on lower incomes. This is also confirmed in my study in women at risk of GDM, which found that income was the strongest predictor of health literacy; these participants ranged in age from 19 years to 49 years and the majority were employed and earned an income (88%). However in an older population income may not predict health literacy, as people in this age bracket are mostly no longer in paid employment. The strength of association and predictive power of income will vary according to the demographics of study participants, other baseline characteristics and the prevalence of limited health literacy of study samples. Similarly demographic factors associated with select populations may not be associated with health literacy in the general population.

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Combining a number of risk factors may improve the prediction of limited literacy. For example Miller et al. developed a predictive model of limited health literacy using the variables of gender, age, education and ethnicity, and found that the model correctly classified 73% of an elderly subgroup from the 1992 NALS survey (183). Similarly Martin et al. developed a predictive model of health literacy, which allows estimation of population health literacy from available census data (184). The authors included in the model variables known to predict health literacy and others strongly hypothesized to be associated with health literacy, which were included in the US national population literacy survey (NAAL, 2003) and available from census data. The analysis extracted the data on health literacy from the NAAL results. The variables used in the model were gender, age, ethnicity, education, income, marital status, language spoken in home, rurality and time in US. Results indicated that use of the predictive model explained almost double the variance compared with using education alone, 30% versus 15.5% and more than double the variance explained by income alone, 30% versus 11%.

Many objective measures of health literacy have the disadvantage of being time-consuming, require training and can be labour-intensive to administer, and patients can feel intimidated or have feelings of inadequacy if they are struggling with the answers. For these reasons these objective measures can be difficult to administer in busy clinical settings, where both time and space are limited and are better suited in research settings. On the other hand subjective measures are preferred by patients and, if they can be delivered in a few minutes, can be more attractive to patients and clinical staff alike. The objective measure I used in my study, the NVS (U.K.), was quick to administer (3 minutes) and from my research I can conclude it is suitable to administer even in busy clinical settings. From administering the HLS-Q and from my results I also recognise that using the HLS-Q in clinical settings would be time-consuming for patients and staff. Shorter, subjective measures which can rapidly estimate health literacy and

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which have acceptable correlations with objective measures of health literacy could be employed in clinical settings. If these measures could be shown to predict clinical outcomes then this would further support their use in clinical practice. Screening questions, such as those in the SLS, also have the advantage in directly comparing the patient's abilities with the literacy demands of the health service and can guide use of interventions to address a mismatch, when identified.

McNaughton et al. conducted a regression analysis on a number of variables and a short subjective measure of health literacy (the SLS) using the S-TOFHLA and the REALM as outcome measures (185). The SLS was a stronger predictor of the S-TOFHLA than education, gender, age and race, accounting for 36% for the S-TOFHLA and 38% for the REALM ( $p<0.05$ ). The area under the curve (AUC) for the receiver operator curve (ROC) for the SLS using the S-TOFHLA as standard was 0.74 (95% CI 0.68, 0.80) and using the REALM was 0.72 (95% CI 0.65, 0.78), indicating good performance in predicting health literacy. In addition, inclusion of the SLS in a predictive model of health literacy with education, age, gender and ethnicity, increased the variance of the model in explaining health literacy by 15.5%. These results indicate that these short subjective measures of health literacy measure different and/overlapping aspects of the construct of health literacy and can improve prediction of health literacy. Further research is needed to test how well short subjective measures of health literacy are associated with health outcomes. Similar findings were reported by Wallace et al. using the 3 items in the SLS, who reported that the screening question "How confident are you filling out medical forms by yourself?" was a better predictor of health literacy (measured by the REALM) compared to a demographic model that included age, ethnicity and education (186).

Some authors, such as Altin et al. recommend using a mixed methods approach, combining objective and subjective measures, and thereby testing a broad range of health literacy skills. Mixed methods and use of

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comprehensive measures are likely to measure more aspects of the construct of health literacy. However there is limited data on the performance of comprehensive measures such as the NALS and the EU HLS as predictors of health outcomes and shorter measures such as the S-TOFHLA, the REALM and the NVS have been shown to significantly predict a number of health outcomes. As an objective measure of health literacy the NVS is short and is likely to be more acceptable to patients as it uses a nutritional food label, which patients are likely to encounter and be familiar with compared with the word lists or selection of single best option items in the REALM and TOFHLA respectively. Use of short objective and subjective tools which have been validated against more established objective measures, and which are associated with health outcomes can achieve Altin's recommendation for mixed methods and be acceptable to patients.

To answer the question what is the best tool or tools to use to measure health literacy one needs to consider the purpose of gathering this information. If, for example, the aim is to determine levels of low health literacy in the general population, to inform and guide public health and health policy makers then a predictive tool that can use available socio-demographic data, such as those developed by Miller et al. and Marin et al. will provide estimates of low health literacy. Such tools will need to be developed and tested at national levels for countries to determine the predictive model that performs best in the target population. On the other hand, in local community or select groups, where more accurate estimates of low health literacy in groups and individuals are required, employing a short objective and/or a short subjective measure of health literacy is more appropriate. This will allow tailoring of resources, communication and interactions between the health service and patients at the levels of access and utilisation of health care, provider-patient interaction and self-care, as detailed in the conceptual model linking health literacy to health outcomes by Paasche and Wolf (78).

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In summary use of health literacy measures and adding these to demographics in predictive models increase the strength of prediction of models of health literacy. Shorter measures and screening questions provide more practical ways of measuring health literacy and a number have been tested and shown to have good correlations with longer (original) versions and objective measures and enhance the predictive strength when added to models. Performance of these shorter measures needs to be tested in selected patient groups and the ability to predict health outcomes and improve prediction when added to demographics in target groups will need to be determined. By doing so, researchers can establish which of the short objective and subjective measures best perform in different patient groups, guiding other researchers and clinicians in identifying patients at risk of low health literacy.

#### **4.7 Health literacy, pregnancy-related factors and adverse pregnancy outcomes**

##### *Pre-pregnancy folic acid*

Almost two thirds of my participants had taken folic acid pre-pregnancy. Folic acid is recommended peri-conceptually since the early 1990s when research showed that this could reduce the first occurrence or reoccurrence of neural tube defects (187). The uptake on pre-pregnancy folic acid in Ireland has greatly improved since the late 1990s', when it was reported in only 16% of a sample of pregnant women attending 3 maternity hospital in the East coast of Ireland (188). The authors reported that having a planned pregnancy and not have a medical card, which was interpreted as a marker of affluence and a higher educational attainment, were predictors of taking pre-pregnancy folic acid. In my study I found a statistically significant difference in rates of pre-pregnancy folic acid between those who had limited and those who had adequate functional health literacy; 53.5% versus 67.8%. My findings that functional health literacy was significantly higher in those with higher incomes, higher educational attainment, private health insurance and those who took pre-pregnancy folic acid are suggestive that health literacy may have been a factor linking a higher pre-pregnancy folic acid uptake in those who did not have a medical card in the study in the East of Ireland. Following adjustment for household income, parental ethnic background and education attainment, functional health literacy was no longer significantly associated with pre-pregnancy folic acid. As discussed in section 4.1 this may indicate functional health literacy is associated with pre-pregnancy folic acid but that confounders are more strongly associated with pre-pregnancy folic acid than functional health literacy. Alternatively it may be that the association with functional health literacy is driven by confounders such as income.

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### *Breast feeding (first feed)*

The breast feeding initiation rate was 65.6% in my study. The 2003 Survey of Lifestyles, Attitudes and Nutrition in Ireland (SLAN) reported that 32% of all mothers in Ireland initiated breast feeding (189). More recently Ladewig et al. report on breastfeeding rates from September 2008 to April 2009 from the Growing Up in Ireland longitudinal study (190). The authors report an overall breast-feeding initiation rate of 56%. The annual report from the National Maternity Hospital, 2015, reported a breast feeding initiation rate of 74% (191). These figures confirm a trend of increasing rates of breast feeding initiation in Ireland in recent years, which may reflect breast feeding policies and campaigns in recent years.

There are a number of known predictors of breast feeding initiation; these include increasing maternal age, maternal grandmothers having breast-fed, non-smoking, higher social class and higher education attainment. Recently Ladewig et al. reported that breast feeding initiation was higher in mothers who were born outside of Ireland (82.2%) compared to mothers who were born in Ireland (48.8%), a difference which was statistically significant (190). My results add to this list of predictors, with the finding that the women who initiated breast feeding had higher functional health literacy compared to those who did not initiate breast feeding; this difference was statistically significant at the 0.001 level.

### *Adverse maternal outcomes*

#### *GDM*

There was a trend whereby GDM was associated with lower NVS scores, suggesting a link between limited functional health literacy and GDM. This trend did not reach statistical significance, which may reflect that there is no difference or that the sample size was insufficient to detect a statistically significant difference, if present. While there are no reported studies on health literacy and GDM there is some evidence that socio-

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demographic factors associated with health literacy are associated with increased risk of GDM. For example a large Australian study of GDM between 1995 to 2005 identified that women of South Asia origin were at the highest risk of developing GDM; they also identified that the risk of developing GDM was approximately two thirds higher in women living in the lowest socio-economic postal areas compared to women living in the highest socio-economic postal area (117). A study in Taiwan found that pregnant women with GDM (n=106) were more likely to have a lower level of education than those with normal glucose tolerance (n=406) (192). Innes et al. conducted a large study in 23,395 pregnant women in New York state and found that the risk of GDM was inversely related to the level of education (193). Similarly a study in 700 pregnant women in Italy found that higher levels of maternal education were associated with lower risk of GDM (194). However studies in Chinese and Iranian pregnant women did not find an association between health literacy and education or occupation (194). In the Italian study the authors report a higher levels of GDM in those who were unemployed or blue collar employment compared with pregnant women in white collar employment. Endres et al. conducted a small study (n=74) in pregnant women with pregestational diabetes and health literacy (104). Low functional health literacy was statistically associated with ethnic minorities, educational attainment and employment. In terms of pregnancy outcomes the study found a higher rate of macrosomia in those with low functional health literacy. There was no difference in rates of prematurity, Caesarean section delivery, shoulder dystocia, or neonatal intensive care admission rates. Ehrenthal et al. studied functional health literacy and postpartum care in women after pregnancy complicated with GDM and or a hypertensive disorder of pregnancy (pre-eclampsia, gestational hypertension or Haemolysis, Elevated liver enzymes, Low platelet count (HELLP) syndrome) (106). A total of 249 women participated, of which 127 had GDM and 111 had a hypertensive disorder of pregnancy. Functional health literacy was measured with the REALM-SF. GDM, gestational hypertension and pre-

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eclampsia are conditions which all carry risk of adverse pregnancy outcomes for the neonate and the mother. In the case of GDM and gestational hypertension there is increased lifetime risk of diabetes and cardiovascular disease. The authors found that women with a REALM-SF score consistent with less than high school education were less likely to attend for follow up screening for diabetes, dyslipidemia and hypertension. Other factors which were also associated with a lower attendance at follow-up care were lack of private health insurance, a lower social-economic class or not having a third level qualification (106).

### *Other adverse Maternal Outcomes*

My results found that NVS scores were lower in those with the maternal adverse outcomes of gestational hypertension and pre-eclampsia. The rate of gestational hypertension was higher in those with limited functional health literacy (8.6%), compared to the rate in those with adequate functional health literacy (5.1%). A similar trend was found with pre-eclampsia where 4.3% of those with limited literacy and only 0.5% of those adequate literacy had this complication. Numbers were small. Larger studies in population samples or cohorts at higher risk of adverse pregnancy outcomes are required to test if these trends are significant. NVS scores and the rate of limited functional health literacy were similar in those with a vaginal delivery and those with a Caesarean section delivery. Only one study in Iran in 150 pregnancies, which used a non-validated health literacy measure, reported on health literacy and Caearean section: the authors reported a higher Caesarean section rate in those with adequate literacy (103). Higher birth weights in the adequate literacy group and other local practices may have contributed to this finding.

### *Adverse Neonatal outcomes*

My results found lower NVS scores in participants who had neonates who were preterm, had macrosomia and/or were LGA. Overall the number of pregnancies with these adverse outcomes was low and differences

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observed did not reach statistical significance. The study by Aimee Moynihan on functional health literacy and prematurity did not find a significant difference in functional health literacy, as measured with the REALM, between the mothers who had premature neonates and matched controls (105). There was a higher percentage of inadequate health literacy in the preterm group and numbers in both groups were small. Kohan et al, who used a measure of health literacy developed by themselves, did a study in 150 pregnant women and found that preterm delivery was higher in the lower health literacy group(103). Endres et al. who looked at health literacy in pregestational diabetes found that the group with low functional health literacy had a higher rate of macrosomia which is in agreement with the trend found in my results in women at risk of GDM. Larger studies are required to determine if these differences are replicated and, if so, if they are statistically significant. Endres et al. did not find any difference in the rate of neonatal intensive care unit admission between the low and adequate literacy groups. Numbers were small with a total of 74 participants with pregestational diabetes. In my study NVS scores in the women who had neonates with SGA and admission to the neonatal intensive care unit were similar to those who did not have these adverse outcomes. They did not report on SGA as an adverse neonatal outcome.

It is evident that there is insufficient research on health literacy and both maternal and neonatal adverse outcomes. At present we can only draw from published data on the association between adverse outcomes and demographic factors, which are also associated with health literacy. For example the analysis by Lou et al on pregnancy outcomes over 10 years in Quebec found that educational attainment and income were significantly associated with prematurity, SGA, stillbirths and neonatal deaths (99). In Ireland the perinatal mortality report 2014, found associations between this adverse pregnancy outcome, and both the educational attainment and mothers from ethnic minority groups (100). It may be that health literacy levels, which have been shown in numerous studies to be associated with

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education, income and ethnicity, are also associated with these adverse pregnancy outcomes. Whether or not, such an association, if established, is an independent predictor of adverse pregnancy outcomes or is driven by confounders, cannot be answered at this time. Further larger studies are needed to answer these questions.

#### **4.8 Correlation between functional health literacy and general health literacy measures**

The Spearman's rho correlation between NVS and the GEN-HL is -0.04 and demonstrates no correlation between the 2 measures of health literacy. In the EU HLS Spearman's rho between these 2 health literacy measures was statistically significant but correlation was low with  $r = 0.245$ . The explanation for these findings may be that each of these measures, measure different constructs of health literacy and one is an objective measure, while the other is a subjective measure of health literacy. The EU HLS measures health literacy across 3 domains (health care, disease prevention and health promotion) and the competencies assessed are access, understand, evaluate and apply health information. The survey is subjective, as it asks the participant to self-report his/her ability to do the tasks in the 47 items of the measure. By comparison the NVS is an objective measure of health literacy and tests print literacy and numeracy literacy; this measure contains 6 task performance items. These 2 tools measure different aspects of the construct of health literacy; the NVS (U.K.) measures functional health literacy which is the lowest dimension of health literacy in Nutbeam's model of health literacy, while the EU HLS-Q measures health literacy at the next level (interactive literacy) in this model, in different domains (195). Other studies which used 2 measures of health literacy, one objective and one subjective measure, found similar low or no correlation between the 2 measures (196, 197).

#### **4.9 Measured health literacy and self-rated health literacy**

Ninety eight percent of participants self-reported their health literacy as adequate or higher. In contrast adequate functional health literacy, as measured with the NVS U.K., was found in 74.7% of participants. Adequate general health literacy, as measured by the EU-HLS, was found in only 62% of participants. Studies have been conducted which have used screening health literacy questions and compared these with validated functional health literacy measures. Validation of a number of self-reported screening questions have shown satisfactory correlation with the TOFHLA and the REALM (198, 199). Stagliano et al. reported that the screening question “How confident are you filling out medical forms by yourself?” was a good predictor of limited health literacy as measured by the NVS (200). Wallace et al. also report this screening question, “confidence with forms”, as being a good predictor of limited functional literacy (186). However there is evidence that patients tend to over-report their reading level which raises the possibility that patients could also over-report their level of health literacy (201).

There are a number of factors which may contribute to the difference found between measured and self-reported health literacy in my study. Firstly I explained the concept of health literacy as “Health literacy refers to your level of understanding of information about your own health, general health information and information about the health service” and asked participants to self-report their health literacy based on this definition. Those with limited text literacy may have had difficulty understanding this explanation. Secondly, as discussed, there is a recognised tendency of patients to over-report literacy levels. Thirdly there is much variability in levels of limited health literacy, depending on the measure employed. For example when compared with 5 other measures of functional health literacy, including the REALM and the S-TOFHLA the NVS measured 48% of a sample as having limited health literacy compared with the S-TOFHLA which only categorised 7.5% of the same sample as having limited health

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literacy (48). On reflection it may have been more appropriate to use one or more of the validated screening questions, e.g. the SLS, for limited health literacy rather than this question. This would have allowed validation of the screening questions against the 2 measures used in my study in this cohort.

## Chapter 5: Conclusions

### 5.1 Conclusions

There has been little research on health literacy in pregnant women internationally and no prior studies in Ireland. My findings demonstrate that limited health literacy is common in pregnant women at risk of gestational diabetes attending the antenatal services in University Hospital Galway.

Measurement of health literacy in this cohort can identify patients with limited health literacy to the service providers; education and training of healthcare professionals could then lead to use of plain language and checking of understanding of health information and instructions given to these patients. Information on the prevalence of limited health literacy in patient groups attending health care services can allow management to adapt measures known to improve communication, such as presentation of essential information only in printed materials, use of illustrations and use of video recordings. This will lead to improved patient understanding, adherence with medications and improved self-care.

Deciding on which is the best measure can be done by testing measures in target patient groups and adding these to demographic variables in predictive models in selected patient groups. Using short measures which are validated and tested in the target groups are likely to enhance strength of prediction, when added to demographic variables, but this needs to be confirmed. Inclusion of a verbal test, such as a screening question, which does not require reading ability, may capture participants with reading and/or writing difficulties, and who are likely to be at risk of limited health literacy.

My findings confirm that there is a social gradient in health literacy in women at risk of GDM. Predictors found to independently predict limited health literacy in the study sample, such as income, education and ethnicity, have also been found in population studies and in studies in

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other patients groups. A number of risk factors for GDM are also risk factors for limited health literacy; these include lower socio-economic class, lower education, employment status, ethnic minorities. These associations supports the possibility of a significant association between GDM and health literacy.

Significant associations between health literacy and pregnancy-related factors and adverse pregnancy outcomes were only noted in pre-pregnancy folic acid and this association was no longer significant after adjustment for confounders. Larger studies are required to determine whether the association between health literacy and pre-pregnancy folic acid is independent or if it is dependent on confounders. No significant associations were found between adverse pregnancy outcomes and health literacy. For GDM there was a trend, where there was a higher percentage of those with limited health literacy diagnosed with GDM compared to those with adequate health literacy. As my sample was relatively affluent and healthy, with a low incidence of adverse pregnancy outcomes, it may be that health literacy is not associated with adverse outcomes in this group. Alternatively my sample size may have been too small to detect significant associations, if present.

Finally my study has identified several health-related tasks, of public health importance, that pregnant women find difficult. These include understanding information on food packaging, understanding the leaflets that come with medicine and deciding if they should have a flu vaccine.

## **5.2 Strengths**

My study had a high response rate with a completion rate of 97.7%. This makes my sample generalizable to the population of women at risk of GDM attending obstetrical services at University Hospital Galway. My data on demographic and socio-economic characteristics of participants was collected through self-completion of a questionnaire, which is more accurate than data collected from hospital records, which can be inaccurate if not updated at regular intervals. This study was a prospective study with health literacy measured several months before delivery and outcomes took place. Measurement of health literacy was multidimensional using a mixed measure, combining a self-report measure of health literacy skills (EU-HLS) and a direct test of functional health literacy (NVS (U.K.)).

Measurement was multidimensional, testing functional health literacy (reading, comprehension and numeracy literacy) and the skills of accessing, understanding, evaluation and application of health information. This multidimensional approach provides a comprehensive measurement of health literacy skills. Almost all of the research to date on health literacy and health outcomes are based on functional health literacy measurement only.

Finally GDM was diagnosed according to the IADPSG diagnostic criteria, which have been endorsed by the WHO, American Diabetes Association and both the European Board & College of Obstetrics and Gynaecology and the International Federation of Gynaecology and Obstetrics.

### **5.3 Limitations**

This is a single centred study and findings may not be generalizable across other geographical areas in Ireland. As I selected pregnant women at risk of GDM, my findings on health literacy levels, may likewise not be representative of all pregnant women in the region. The participants agreed to participate as it was convenient for them to do so at the time of their visit to the outpatients department in University Hospital Galway; by definition this was a convenience sample. As discussed there is risk of bias in the participant selection, gathering of the information and the role of confounders. Our sample size may have limited our ability to detect significant associations between health literacy and socio-demographic factors and adverse pregnancy outcomes. It remains unclear whether health literacy is independently associated with pregnancy outcomes and, if so, whether this is dependent on confounders. Seventeen pregnant women did not meet the eligibility criteria because of poor English language skills; these women were likely to have non-Irish parents and may have been at increased risk of limited health literacy. Finally a mixed methods approach, with inclusion of focus groups and/or semi-structured interviews, would have strengthened this study and permitted exploration of associations of limited health literacy which may influence any and all aspects of healthcare across domains and processes.

#### **5.4 Future directions**

This is the first study on health literacy in pregnant women in Ireland. Larger multi-centred studies, using validated health literacy measures, are required to determine if the findings in this study are replicated and if the prevalence of limited health literacy in pregnant women in general is similar to that in women at risk of GDM in this study. Studies in cohorts, known to be at higher risk of adverse pregnancy outcomes, could be conducted to determine if limited health literacy is associated with adverse pregnancy outcomes. These cohorts include pregnant women with GDM, raised BMI or from low socio-economic backgrounds. Another area that I recommend research into is postpartum follow-up in women after GDM and gestational hypertension, who are at an increased risk of cardiovascular disease later in life, to determine if health literacy is associated with completion of follow-up testing. Qualitative studies should also be included to provide insights into the processes linking health literacy with health and healthcare in pregnant women at risk of adverse outcomes.

Use of screening questions and validation and testing their performance in pregnant cohorts may facilitate a quick and easy assessment of health literacy in clinical settings. Screening questions, if shown to have good correlation with established objective measures of health literacy, such as the NVS (U.K.), could be used instead of comprehensive measures of general health literacy, such as the EU HLS-Q.

GDM and health literacy share a number of common risk factors. The role of limited health literacy as a potential risk factor and/or predictor of poorer outcomes in pregnant women with GDM could be explored in a health literacy study in this cohort of patients. A multi-centred approach would be feasible if this is conducted through the ATLANTIC DIP programme.

## Conclusions

Finally all research on health literacy serves to raise awareness among health care providers that not all patients they provide service to have adequate health literacy skills. As Regina Benjamin, the 18<sup>th</sup> Surgeon General of the U.S. states:

“....health professionals cannot assume that everything we tell our patients is perfectly clear to them. What we say doesn’t matter as much as what patients understand, remember, and do. If their understanding is incorrect or incomplete, we did not find the right way to reach them.”

Benjamin, 2010 (152)

## Conclusions

## Section 6: References

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## Section 7: Appendices

### Appendix A: Protocol for screening and OGTT in UHG

#### Screening for Gestational Diabetes Mellitus

Pregnant women should be categorised into one of the following three groups:

##### 1. HIGH RISK

Women with any one of the following risk factors should undergo an oral glucose tolerance test (OGTT) as soon as is feasible. If a woman is found not to have gestational diabetes mellitus (GDM) at this initial screening, she should be re-tested between 24-28 weeks gestation.

- Body mass index >30Kg/m<sup>2</sup>
- Prior history of GDM or delivery of large-for-gestational-age infant
- Presence of glycosuria
- Diagnosis of polycystic ovarian syndrome (PCOS)
- Strong family history of Type 2 diabetes
- Ethnicity (all ethnic sub groups)

##### 2. MEDIUM RISK

A woman with any one of the following risk factors should be screened at 24-28 weeks gestation.

- Body mass index 25-30Kg/m<sup>2</sup>
- Maternal age > 30 years
- Long-term steroids
- Previous unexplained perinatal death
- Polyhydramnios and/or macrosomia in existing pregnancy

##### 3. LOW RISK

Women with ALL of the following characteristics do not require screening:

- Age < 25 years
- Eight normal before pregnancy (body mass index ≤ 25Kg/m<sup>2</sup>)
- Caucasian
- No known diabetes in first-degree relatives
- No history of abnormal glucose tolerance
- No history of poor obstetrical outcome

## Appendices

### Guidelines for 75g OGTT

1. Advise the patient not to eat or drink anything other than water for 12 hours before the test.
2. Advise the patient to refrain from smoking from midnight the night before the test.

### Fasting glucose should be taken before 10.00AM

1.	Prepare Polycal Drink – NB see below
2.	Obtain a venous glucose sample in the grey fluoride oxalate bottle
3.	Gently invert the sample five times to mix the contents
4.	Label the sample and laboratory form with patient's details
5.	Label the bottle and laboratory form 'Time 0 hours'
6.	Ensure that the sugar solution is fully dissolved and there is no sugar at the bottom of the glass after the patient has drank the solution.
7.	Note the time the patient finished the glucose drink in the next column.
8.	Advise the patient to 1) rest for the next hour until the next part of the test* 2) remain fasting until test is complete (100mls water only to be sipped over the space of two hours.) 3) Abstain from smoking
9.	On returning one hour later, check that the patient has been compliant with the above instructions (if not do not proceed with the test).
10.	Check that it is 1 hour since the glucose drink was consumed.
11.	Obtain a glucose sample in the grey fluoride oxalate bottle.
12.	Invert gently five times to mix the contents.
13.	Label the sample and laboratory form with patient's details.
14.	Label the bottle and laboratory form 'Time 1 hour'
15.	Advise the patient to: 1) rest for the next hour until the final part of the test* 2) remain fasting until test is complete (continue to sip on the water). 3) abstain from smoking.
16.	On returning one hour later, check that the patient has been compliant with the above instructions (if not, do not proceed with the test)
17.	Check that it is now two hours since the glucose drink was consumed.
18.	Obtain a glucose sample in the grey fluoride oxalate bottle.
19.	Invert gently five times to mix the contents
20.	Label the sample and laboratory form with patient's details
21.	Label the bottle and laboratory form "Time 2 hours".

- \* Instruct the patient to rest for the next two hours if possible, and to avoid any exercise, even walking. This is to avoid burning calories resulting in a lower glucose level at 1 and 2 hours. Smoking can affect glucose levels and must be avoided until the test is complete.

### Preparation of Polycal for the Oral Glucose Tolerance Test

1. Measure 113ml Polycal into beaker.
2. Make up to a volume of 200mls by adding water
3. Secure plastic cap firmly onto beaker and shake thoroughly.

### Reference

Guideline for the management of Diabetes in Pregnancy. Atlantic DIP, August 2015

**Appendix B: Participant information sheet and consent form**

**PARTICIPANT INFORMATION SHEET Date: 4.01.2016**

Health Literacy Levels in women at risk of Gestational Diabetes Mellitus attending antenatal services in University Hospital Galway

**Introduction:**

You are invited to participate in a research study which aims to gather information from pregnant women who are referred for a glucose tolerance test. The purpose of the research is to check your level of understanding when you receive information, which you may be given verbally (spoken) by medical staff (a nurse or a doctor, for example) or it may be written information, such as a leaflet or prescription. It may include numeracy skills (dealing with numbers) and text (sentences and explanations). Some questions may ask about your ability to find out about health services available to help you make good health decisions for you and your family. These skills are called "Health Literacy".

The reason we are doing this study is that it has been shown that patients that have difficulty understanding health information may find it more difficult to make good decisions about their health. They may also find it difficult to understand all the information they are given by the doctor, nurse, or dietician.

Health care professionals may not be aware of difficulties that some people have in understanding information about health matters. This study will help us to find out about the health literacy of pregnant women who are at risk for developing diabetes in pregnancy.

**Procedure:**

The study will take place during the time that you are in the maternity department for the glucose tolerance test. Firstly you will be asked to complete a form while you are in the waiting area. These will be general questions about you, your health and your social circumstances.

Then you will be brought into a room where the study researcher will ask questions from 2 health literacy questionnaires, which have been used previously in Ireland to check health literacy. The researcher will also access your computer file in the hospital to get additional information about you and the rest of the pregnancy. Blood test results will be taken from the hospital laboratory electronic system.

The study forms will take about 20 minutes and will take place during the time that you are in the maternity department for the glucose tolerance test (which will take 2 hours). All information will be obtained anonymously, which means names and addresses will not be written in the computer results sheet. ONLY THE STUDY RESEARCHERS WILL HAVE THE RESULTS AND THE FILE WILL ONLY OPEN BY USE OF A PASSWORD.

**Inclusion and Exclusion criteria:**

All patients booked in for a glucose tolerance test to the maternity department are eligible to take part in the study. If you have difficulty reading English or understanding spoken English you will not be asked to participate in the study. You must be over 18 years old to participate in this study.

**Benefits/Risks to Participants:**

This study will not cause any risks to you. If you have concerns about your health literacy you can contact the National Health literacy Association (NALA). The website is [www.nala.ie](http://www.nala.ie) or you can phone the freephone number 1800 202065. NALA provides advice and services.

**Compensation:**

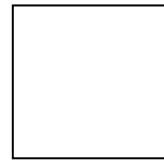
No tangible compensation will be given. A copy of the research results will be available at the conclusion of the study from Dr Yvonne Finn ([yvonne.finn@nuigalway.ie](mailto:yvonne.finn@nuigalway.ie))

**Voluntary Nature of the Study:**

Participation in this study is strictly voluntary, and if agreement to participation is given, it can be withdrawn at any time without affecting yours rights in any way.

**Points of Contact:**

It is understood that should you have any questions or comments regarding this study, the Principal Investigator, Dr Yvonne Finn should be contacted. [yvonne.finn@nuigalway.ie](mailto:yvonne.finn@nuigalway.ie)



### **CONSENT FORM**

Health Literacy Levels in women at risk of Gestational Diabetes Mellitus attending antenatal services in University Hospital Galway

#### **Please tick box:**

1. I confirm that I have read the information sheet dated 04.01.2016 and have had the opportunity to ask questions
2. I am satisfied that I understand the information provided and have had enough time to consider the information
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
4. I agree to take part in the above study

<b>Name:</b>
<b>Address:</b>
<b>Date of birth:</b>

**Signature of participant:**

**Date:**

**Signature of Researcher:**

**Date:**

## Appendices

### Appendix C: Ethics approval statement



Ospidéal na h-Ollscoile, Páirc Mheirlinne  
Merlin Park University Hospital  
GALWAY UNIVERSITY HOSPITALS

Clinical Research Ethics Committee  
Room 59  
1<sup>st</sup> Floor  
HR Building  
Merlin Park Hospital  
Galway.

12<sup>th</sup> November, 2015.

Dr. Yvonne Finn  
Lecturer in Clinical Methods and Clinical Practice  
Clinical Science Institute  
School of Medicine  
NUI  
Galway.

*Ref: C.A. 1379 - Health Literacy Levels in women at risk of Gestational Diabetes Mellitus attending antenatal services in University Hospital Galway*

Dear Dr. Finn,

I have considered and reviewed the above project, and I wish to grant Chairman's approval to proceed.

Yours sincerely,

PP: Shaun O'Keeffe  
Dr. Shaun T. O'Keeffe  
Chairman Clinical Research Ethics Committee.

c.c. Professor Fidelma Dunne, Consultant Endocrinologist, Head of School of Medicine,  
Clinical Science Institute, National University of Ireland, Galway.

Ospidéal na h-Ollscoile, Páirc Mheirlinne, MERLIN PARK UNIVERSITY HOSPITAL,  
Galway, Ireland. Tel: 00 353 (0)91 757631

**Appendix D: Demographic form**



**Health Literacy Levels in women at risk of Gestational Diabetes Mellitus attending antenatal services in University Hospital Galway**

**Questionnaire: please answer all questions. If you have any questions please ask the researcher. All information gathered will be recorded anonymously.**

**1) Age .....years**

**2) How many weeks are you pregnant?  weeks**

**3) What is your legal marital status?**

Not married  Married  Separated/divorced

**4) Regarding smoking cigarettes, which of the following applies to you?**

	<b>Please tick one</b>
1. You smoke at the present time	
2. You used to smoke but you stopped when you found out you were pregnant	
3. You used to smoke but you stopped before you knew you were pregnant	
4. You have never smoked	

**5) What is the highest level of education you have successfully completed (usually by obtaining a certificate or diploma)? Tick one box**

Level 0

Level 1

Level 2

(pre-primary education) (primary education) (lower secondary)

Level 3

Level 4

Level 5

(upper secondary  
education)

(post-secondary/  
non-third level)

third level

Level 6

(third level (postgrad Diploma/Masters / PhD)

**6) Employment status. Which of the following best represents your current employment status?**

Unemployed

Self-employed

Full-time   
employee

Part-time Employee

Student/ in training/   
Unpaid work experience

fulltime homemaker/parent or carer

**7) Which one of the following corresponds to your situation? (tick one box)**

1. Your father and mother were born in Ireland

2. One of your parents was born in Ireland and the other was  
born in another member state of the European Union

3. Your mother and your father were born in another Member State of the European Union

4. One of your parents was born in Ireland and the other was born outside of the European Union

5. Your mother and your father were born outside of the European Union

6. One of your parents was born in another member State of the European Union and the other was born outside the European union

**8) Which of the following best corresponds to your average income?**

Low

Below average

Average

Above average

High

**9) Did you drink any alcoholic beverages (beer, wine, spirits, cider or other local beverages) in the last 30 days?**

1. Yes

2. No

3. Don't know

**10) How often during the last month did you exercise for 30 minutes or longer e.g. running, walking or cycling?**

Almost every day

A few times   
a week

A few times   
this month

Not at all

I haven't been  
able to exercise

**11) How is your health in general?**

Very good

Good

Fair

Bad

Very bad

**12) Health literacy refers to your level of understanding of information about your own health, general health information and information about the health service. Which of the following corresponds, in your view, to your level of health literacy?**

Low /inadequate

Adequate

Above average

High

**13) What kind of health insurance do you have?**

Public (medical card or GP card)

Private

Public and private

None

**Appendix E: NVS (U.K.)**

NVS-UK FINAL APRIL 2012

**SHOW CARD**

**Product Description:** Ice Cream

Serving Size: 100ml  
Servings per container: 4

**NUTRITIONAL INFORMATION**

<b>TYPICAL VALUES</b>	<i>Per 100ml</i>
<b>Energy</b>	1050 kJ 250 kcal (calories)
<b>Protein</b>	4 g
<b>Carbohydrate</b>	30 g
of which sugars	23 g
<b>Fat</b>	13 g
of which saturates	9 g
of which monounsaturates	0 g
of which polyunsaturates	3 g
of which trans fats	1 g
<b>Fibre</b>	0 g
<b>Sodium</b>	0.05 g

**Ingredients:** Cream, Skimmed Milk, Sugar, Whole Egg, Stabilisers (Guar Gum), Peanut Oil, Vanilla Extract (0.05%).

**NVS (U.K) questions and correct responses**

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Instructions: hand label to respondent and give them a minute or so to read it – this is not timed, so give them as long as they need.

Read out: This part of the survey will look at health information on food packaging. This show card gives you the kind of information you might find on the back of a container of ice cream that you just bought at the supermarket. I need you to look at this show card, and then I'm going to ask you to answer some questions. Please have a good read of the information. Let me know when you are finished and we'll move on to the questions.

Question	Yes	No
1. How many calories (kcal) will you eat if you eat the whole container? <i>1,000 KCAL or 1,000 calories is the only correct answer</i>		
2. If you are advised to eat no more than 60 gms of carbohydrate for dessert what is the maximum amount of ice cream you could eat? <i>Two servings (or anything up to 2 servings) OR half the container (or anything up to half the container) OR 200mls (or any amount up to 200mls)</i>		
3. Imagine that your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42g of saturated fat each day, some of which comes from one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be eating each day? <i>33 g is the only correct answer</i>		
4. If you usually eat 2,500 calories each day, what percentage of your daily calorie (kcal) intake will you get from one serving of ice cream? <i>1/10 (one tenth) OR 10%</i>		
Imagine that you are allergic to the following substances: penicillin, peanuts, latex gloves and bee stings. 5. Is it safe for you to eat this ice cream? <i>No</i>		
If no to Q5 6. Why not? <i>Because it contains peanut oil/peanuts/nuts</i>		

One point per correct answer: Maximum score is 6

**Appendix F: HLS-Q**



**Cure and care Managing symptoms, complaints, illness and treatments**

Q1.1 On a scale from very easy to very difficult, how easy would you say it is to: find information about symptoms of illnesses that concern you?

1 Very easy      2 Fairly easy      3 Fairly difficult  
4 Very Difficult      5 Don't know (Spontaneous)

Q1.2-On a scale from very easy to very difficult, how easy would you say it is to: find information on treatments of illnesses that concern you?

1 Very easy      2 Fairly easy      3 Fairly difficult  
4 Very Difficult      5 Don't know (Spontaneous)

Q1.3-On a scale from very easy to very difficult, how easy would you say it is to: find out what to do in case of a medical emergency?

1 Very easy      2 Fairly easy      3 Fairly difficult  
4 Very Difficult      5 Don't know (Spontaneous)

Q1.4-On a scale from very easy to very difficult, how easy would you say it is to: find out where to get professional help when you are ill?

(Instructions: such as doctor, pharmacist, psychologist)

1 Very easy      2 Fairly easy      3 Fairly difficult  
4 Very Difficult      5 Don't know (Spontaneous)

Q1.5-On a scale from very easy to very difficult, how easy would you say it is to: understand what your doctor says to you?

1 Very easy      2 Fairly easy      3 Fairly difficult  
4 Very Difficult      5 Don't know (Spontaneous)

Q1.6-On a scale from very easy to very difficult, how easy would you say it is to: understand the leaflets that come with your medicine?

1 Very easy      2 Fairly easy      3 Fairly difficult  
4 Very Difficult      5 Don't know (Spontaneous)

## Appendices

Q1.7-On a scale from very easy to very difficult, how easy would you say it is to: understand what to do in a medical emergency?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.8-On a scale from very easy to very difficult, how easy would you say it is to: understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.9-On a scale from very easy to very difficult, how easy would you say it is to: judge how information from your doctor applies to you?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.10-On a scale from very easy to very difficult, how easy would you say it is to: judge the advantages and disadvantages of different treatment options?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.11-On a scale from very easy to very difficult, how easy would you say it is to: judge when you may need to get a second opinion from another doctor?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.12-On a scale from very easy to very difficult, how easy would you say it is to: judge if the information about illness in the media is reliable?

(Instructions: TV, Internet or other media)

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.13-On a scale from very easy to very difficult, how easy would you say it is to: use information the doctor gives you to make decisions about your illness?

1 Very easy	2 Fairly easy	3 Fairly difficult
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## Appendices

4 Very Difficult                    5 Don't know (Spontaneous)

Q1.14-On a scale from very easy to very difficult, how easy would you say it is to: follow the instructions on medication?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                    5 Don't know (Spontaneous)

Q1.15-On a scale from very easy to very difficult, how easy would you say it is to: call an ambulance in an emergency?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                    5 Don't know (Spontaneous)

Q1.16-On a scale from very easy to very difficult, how easy would you say it is to: follow instructions from your doctor or pharmacist?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                    5 Don't know (Spontaneous)

### Disease prevention Managing risk factors for health

Q1.17-On a scale from very easy to very difficult, how easy would you say it is to: find information about how to manage unhealthy behaviour such as smoking, low physical activity and drinking too much?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                    5 Don't know (Spontaneous)

Q1.18-On a scale from very easy to very difficult, how easy would you say it is to: find information on how to manage mental health problems like stress or depression?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                    5 Don't know (Spontaneous)

Q1.19-On a scale from very easy to very difficult, how easy would you say it is to: find information about vaccinations and health screenings that you should have? (Instructions: breast exam, blood sugar test, blood pressure)

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                    5 Don't know (Spontaneous)

Q1.20-On a scale from very easy to very difficult, how easy would you say it is to: find information on how to prevent or manage conditions like being overweight, high blood pressure or high cholesterol?

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1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                5 Don't know (Spontaneous)

Q1.21-On a scale from very easy to very difficult, how easy would you say it is to: understand health warnings about behaviour such as smoking, low physical activity and drinking too much?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                5 Don't know (Spontaneous)

Q1.22-On a scale from very easy to very difficult, how easy would you say it is to: understand why you need vaccinations?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                5 Don't know (Spontaneous)

Q1.23-On a scale from very easy to very difficult, how easy would you say it is to: understand why you need health screenings? (Instructions: breast exam, blood sugar test, blood pressure)

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                5 Don't know (Spontaneous)

Q1.24-On a scale from very easy to very difficult, how easy would you say it is to: judge how reliable health warnings are, such as smoking, low physical activity and drinking too much?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                5 Don't know (Spontaneous)

Q1.25-On a scale from very easy to very difficult, how easy would you say it is to: judge when you need to go to a doctor for a check-up?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                5 Don't know (Spontaneous)

Q1.26-On a scale from very easy to very difficult, how easy would you say it is to: judge which vaccinations you may need?

1 Very easy                    2 Fairly easy                    3 Fairly difficult

4 Very Difficult                5 Don't know (Spontaneous)

Q1.27-On a scale from very easy to very difficult, how easy would you say it is to: judge which health screenings you should have? (Instructions: breast exam, blood sugar test, blood pressure)

## Appendices

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.28-On a scale from very easy to very difficult, how easy would you say it is to: judge if the information on health risks in the media is reliable?

(Instructions: TV, Internet or other media)

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.29-On a scale from very easy to very difficult, how easy would you say it is to: decide if you should have a flu vaccination?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.30-On a scale from very easy to very difficult, how easy would you say it is to: decide how you can protect yourself from illness based on advice from family and friends?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

Q1.31-On a scale from very easy to very difficult, how easy would you say it is to: decide how you can protect yourself from illness based on information in the media? (Instructions: Newspapers, leaflets, Internet or other media?)

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

### Health promotion

#### Managing resources for health and wellbeing

Q1.32-On a scale from very easy to very difficult, how easy would you say it is to: find information on healthy activities such as exercise, healthy food and nutrition?

1 Very easy	2 Fairly easy	3 Fairly difficult
4 Very Difficult	5 Don't know (Spontaneous)	

## Appendices

Q1.33-On a scale from very easy to very difficult, how easy would you say it is to: find out about activities that are good for your mental well-being?  
(Instructions: meditation, exercise, walking, pilates etc.)

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult            5 Don't know (Spontaneous)

Q1.34-On a scale from very easy to very difficult, how easy would you say it is to: find information on how your neighbourhood could be more health friendly? (Instructions: Reducing noise and pollution, creating green spaces, leisure facilities)

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult            5 Don't know (Spontaneous)

Q1.35-On a scale from very easy to very difficult, how easy would you say it is to: find out about political changes that may affect health?  
(Instructions: legislation, new health screening programmes, changing of government, restructuring of health service)

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult            5 Don't know (Spontaneous)

Q1.36-On a scale from very easy to very difficult, how easy would you say it is to: find out about efforts to promote your health at work?

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult            5 Don't know (Spontaneous)

Q1.37-On a scale from very easy to very difficult, how easy would you say it is to: understand advice on health from family members or friends?

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult            5 Don't know (Spontaneous)

Q1.38-On a scale from very easy to very difficult, how easy would you say it is to: understand information on food packaging?

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult            5 Don't know (Spontaneous)

Q1.39-On a scale from very easy to very difficult, how easy would you say it is to: understand information in the media on how to get healthier?  
(Instructions: Internet, newspapers, magazines)

## Appendices

1 Very easy      2 Fairly easy      3 Fairly difficult

4 Very Difficult      5 Don't know (Spontaneous)

Q1.40-On a scale from very easy to very difficult, how easy would you say it is to: understand information on how to keep your mind healthy?

1 Very easy      2 Fairly easy      3 Fairly difficult

4 Very Difficult      5 Don't know (Spontaneous)

Q1.41-On a scale from very easy to very difficult, how easy would you say it is to: judge how where you live affects your health and well-being?

(Instructions: Your community, your neighbourhood)

1 Very easy      2 Fairly easy      3 Fairly difficult

4 Very Difficult      5 Don't know (Spontaneous)

Q1.42-On a scale from very easy to very difficult, how easy would you say it is to: judge how your housing conditions help you to stay healthy?

1 Very easy      2 Fairly easy      3 Fairly difficult

4 Very Difficult      5 Don't know (Spontaneous)

Q1.43-On a scale from very easy to very difficult, how easy would you say it is to: judge which everyday behaviour is related to your health?

(Instructions: Drinking and eating habits, exercise etc.)

1 Very easy      2 Fairly easy      3 Fairly difficult

4 Very Difficult      5 Don't know (Spontaneous)

Q1.44-On a scale from very easy to very difficult, how easy would you say it is to: make decisions to improve your health?

1 Very easy      2 Fairly easy      3 Fairly difficult

4 Very Difficult      5 Don't know (Spontaneous)

Q1.45-On a scale from very easy to very difficult, how easy would you say it is to: join a sports club or exercise class if you want to?

1 Very easy      2 Fairly easy      3 Fairly difficult

4 Very Difficult      5 Don't know (Spontaneous)

Q1.46-On a scale from very easy to very difficult, how easy would you say it is to: influence your living conditions that affect your health and well being? (Instructions: Drinking and eating habits, exercise etc.)

## Appendices

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult              5 Don't know (Spontaneous)

**Q1.47-On a scale from very easy to very difficult, how easy would you say it is to: take part in activities that improve health and well-being in your community?**

1 Very easy                  2 Fairly easy                  3 Fairly difficult

4 Very Difficult              5 Don't know (Spontaneous)

### Additional Questions from the HLS-EU ((Ireland) Demographics

**Q1. 48. On the following scale, step '1' corresponds to "the lowest level in the society"; step '10' corresponds to "the highest level in the society". Could you tell me which step you would place yourself?**

	<b>Tick one box</b>
1. The lowest level in society	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10. The highest level in society	
11. Refusal (SPONTANEOUS)	

**Q1.49.-What is your household's net income per month?**

	<b>Tick one box</b>
1. Less than €800	
2. €800 to under €1,350	
3. €1,350 to under €1,850	
4. €1,850 to under €2,400	
5. €2,400 to under 2,950	
6. €2,950 to under €3,600	
7. €3,600 to under €4,400	
8. €4,400 to under 5,250	
9. €5,250 to under €6,450	
10. €6,450 or more	
11. Refusal (SPONTANEOUS)	