

A Study of Maternal Reports of Childhood Injuries that Result in
Hospital Attendance or Admission: do they Match National
Health Index Database Records?

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List of Abbreviations

Abbreviation	Definition
AC	Acute event
ACC	Accident Compensation Corporation
AUT	AUT University
AUTEC	Auckland University of Technology Ethics Committee
DHB	District Health Board
DOB	Date of Birth
EC	Emergency clinic
ED	Emergency department
GP	General Practitioner
ICD	WHO International Classification of Disease 10 th edition, Australian modification - ICD codes
ID	Identification code
IPV	Intimate partner violence
MOH	Ministry of Health
NHI	National Health Index
NMDS	National Medical Discharge Summary
NNPAC	National Non Admitted Patient Collection

NZ	New Zealand
NZHIS	New Zealand Health Information Service
NZCYES	New Zealand Child and Youth Epidemiology Service
OPC	Outpatient clinic
PIF	Pacific Islands Families
PPAB	Pacific People's Advisory Board
RCT	Randomized Controlled Trial
SES	Socioeconomic status
SPC	Specialist
SUDS	Sudden Unexplained Death Syndrome
UK	United Kingdom
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization
WN	Waiting list event

Nomenclature

Term/symbol	Definition
α	alpha
CI	confidence interval
κ	Cohen's kappa statistic
χ^2	Goodness of fit test
P	P-value

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed:

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Abstract

Background

Childhood injury is one of the leading causes of morbidity and mortality worldwide and concern is increasingly expressed at the lack of adequate data to inform policies and injury prevention strategies.

Objective

The aim of this thesis was to examine the reliability and validity of the use of maternal recall of childhood injuries in a birth cohort study of Pacific mothers residing in New Zealand. Maternal reports of child injuries and medical attendance events reported were matched to listings held within the National New Zealand Health Information Service (NZHIS), computer database of public hospital events, the National Medical Discharge Summary (NMDS) database.

Methods

The study included 1,354 Pacific children born in Auckland in 2000 whose mothers completed a questionnaire at 6-weeks, 1-year, 2-years, 4-years, and at the 6-year measurement waves. Mothers identified injury events by proxy report, in face to face interviews with ethnic specific interviewers. Information was gained on the type of injuries sustained, their frequency and medical attendance events associated with these injuries. The Statistical Classification of Diseases and Related Health Problems Code 10th Revision (ICD-10-AM) was used to ascertain injury and non injury status for the NMDS medical attendance listings.

Results

Kappa statistics demonstrated a modest level of agreement between the NHI database listings and the mothers reporting of childhood injuries between the 0-6-year old children. However McNemar's test of symmetry revealed no systemic under-reporting on behalf of the mothers, suggesting that the use of maternal proxy reporting of childhood injuries is indeed a valid measure.

Conclusion

While maternal proxy reporting of childhood injuries was found to be a valid measure, some evidence of misinterpretation of questions was found; suggesting continued vigilance and development of maternal completed childhood injury questionnaires is warranted. Further investigation exploring the reliability of maternal recall over time and development of an internationally recognised and standardized questionnaire for capturing parent reports of childhood injury is advocated. The responsible use of de-identified data in child health studies is believed to have a pivotal role to play in reliability and validity studies in the future.

1: Introduction

“Health is a depiction of the age; the health status of a society is an imprint of a given period” (Kokeny, 2006, p.133).

1.1 Background

Intentional and unintentional childhood injuries are increasingly being recognized as one of the leading causes of morbidity, mortality and disability in children worldwide (World Health Organization (WHO) & United Nations International Children’s Emergency Fund (UNICEF), 2008). By children’s very nature and developmental level they are inquisitive, and their exploration of the world and subsequent safety is influenced by many factors (Towner & Towner, 2001; WHO & UNICEF, 2008). These include their social, physical, cognitive and psychological attributes, and environments. Consequently the aetiology and presentation of injuries change as they progress from infancy into childhood. Despite high rates of injury having been alluded to for many generations, this area of childhood health is in fact deemed to be an emerging public health field. It is widely acknowledged that the true picture of the extent of injury is yet to be uncovered, particularly unintentional injuries (Towner & Towner, 2001; WHO, 2006; WHO & UNICEF, 2008).

A contributing reason to this lack of knowledge has been the low priority given to addressing childhood injuries. In 1966 the National Academy of Sciences heralded injuries as being “the neglected disease of modern society” in the title of their seminal report on injuries in America (National Academy of Sciences, 1966). Today, many decades later, debate still continues as to why there is deemed to be a ‘policy vacuum’ in the realm of child hood injury prevention, with such endeavours being recognized to ‘lag behind’ other public health initiatives. Challenges also prevail as to whom the responsibility lies with for addressing the unacceptable levels of childhood injuries that continue to persist in the majority of countries around the world (Harvey, Towner, Peden, Soori, & Bartolomeos, 2009; Tremblay & Peterson, 1999). Roberts, Smith, and Bryce (1995) aptly state considering the concerning level of childhood injuries the lack of attention given is “at best curious - at worst scandalous” (p.7).

Lopez (2008) challenges that WHO's continued funding of communicable diseases at higher levels than those for non communicable diseases or injuries is unacceptable. He prompts reflection on the status of injury prevention initiatives that receive the bare minimum of funds in regular budget allocation; despite injuries causing 12-13% of the entire global burden of disease and injury and many being preventable in nature. The 2008 World Report on Childhood Injury Prevention advocates increased attention and allocation of resources are imperative to reduce the injury morbidity, mortality, reduce disability and to subsequently improve the health and wellbeing of children (WHO & UNICEF, 2008). One might propose that within their own organisation they also need to address such allocation of resources themselves, given that they have the ability to lead by example to influence nations around the globe.

The need for governments and governmental agencies to provide strong leadership and promote multisectorial approaches to ensure action is undertaken to promote the health and wellbeing of children, through the prevention of injuries is recognized to be imperative (WHO & UNICEF, 2008; WHO, 2010). The WHO identifies that countries that have achieved the greatest reduction in reducing their burden of childhood injuries have displayed a strong degree of political will and commitment to ensuring adequate resources, systems, policies, and research are undertaken in a multisectorial and multilevel manner. The ultimate goal is to foster a climate that cultivates a safer environment for children (WHO, 2008).

In New Zealand concern has been raised about the fragmentation of government and non government agencies working in the field of childhood injuries and indeed the wider realm of child health. The need for identification of a specific agency to fulfil a comprehensive leadership role in these fields has been recently advocated (Reeve, 2006; Public Health Advisory Committee, 2010). Pivotal to the success of any such initiatives is adequate data to inform policies, in order to gain a greater understanding of the factors that are associated with childhood injuries (Lyons, Brophy, Pockett, & John, 2005; WHO & UNICEF, 2008). Both within the New Zealand context and internationally comprehensive injury data availability and quality have been identified to be lacking, which has resulted in challenges for researchers to identify these factors to facilitate effective preventative programmes (WHO 2008; Schluter, Paterson, & Percival, 2006).

1.1.1 Childhood injuries – the New Zealand context

It was indeed a sad indictment on our society when in 2007 a UNICEF report identified New Zealand was ranked the lowest overall of 24th out of 24 OECD countries for ‘deaths from accidents and injuries per 100 000 under 19 years of age’ (UNICEF, 2007). Given the extent of the problems that injuries pose to individuals and their communities, society has a moral responsibility to work towards minimising the impact of injuries. Nowhere is this more pertinent than in the case of children and especially children who fall within multiple categories of inequalities in health – as is the case for Pacific Island children living in New Zealand. It is known that Pacific Island children comprise 8.4% of New Zealand children hospitalized for non intentional injury, despite only representing 7.6% of the population (Ministry of Health (MOH), 2008c).

1.2 Statement of the Problem

Accurate data provides the platform on which to develop comprehensive injury prevention policies and interventions. High quality data is essential for valid inferences to be drawn. Accurate data provides a robust foundation that is “essential for identifying, prioritizing issues, high risk groups and understanding the burden of injury” (WHO, 2006, p.11). Governments, policymakers, planners and funders can develop health strategies, programmes and initiatives based on the findings. It goes without saying that it is imperative to ensure such information is correct (Macarthur, Dougherty, & Pless, 1997; Stokes, Ozanne-Smith, Harrison, & Steenkamp, 2000). Evidence based practice is an important consideration and crucial component of planning and policy development. Robust data is identified as having a pivotal role to play in informing these decision making processes (McKenzie, Enraght-Mooney, Waller, Harrison, & McClure (2009). Without adequate quantity and quality of data the ability to influence policy makers is constrained (WHO, 2008).

Ultimately research that does not seek to ensure the methods used to obtain data are valid run the risk of endangering public health by resources being directed to an area that may not need it, an issue especially pertinent for those in society whom already experience inequalities in their health status. Inadequate data can lead to an under or over estimation of injuries. In today’s world of finite financial resources, these biases could potentially lead to devastating consequences by the provision of ineffective policies or initiatives, which could in fact compound existing inequalities. (Beauchamp et al., 1991; Cryer & Langley, 2008; Rivara & Mueller, 1987; Sim & Mackie, 2002).

Unless researchers ensure they undertake their research in the most effective manner possible, while acknowledging the constraints that impact on such research, the very stand on which they claim to enhance knowledge must surely be open to be challenged. In countries that have successfully reduced the injury rates among children a common feature has been that thorough scientific enquiry has been undertaken to research causes of the injuries (WHO, 2006). Gordis (1979) challenged researchers to be aware that with the enthusiasm for increasing technological advances including computer capabilities enhancing data management and facilitating rapid statistical analysis, not to lose sight of the quality of the original data obtained during measurement procedures. This data forms the basis of such analysis and no sophisticated analytical techniques can compensate for inaccurate data obtained by the amount of ineffective measurement tools.

Central to scientific enquiry is the type of measurement tools used and the methods undertaken for researching childhood injuries. The use of maternal recall for reporting of childhood health issues is a commonly used measurement tool and correspondingly is also frequently used in childhood injury research studies. Despite its use being recognized as contentious, validity studies are infrequently undertaken to assess its effectiveness (Chung, Domino, Jackson, & Morrissey, 2008; Mickalide, 1997; Neugebauer & Ng, 1990; Ungar, Davidson-Grimwood, & Cousins, 2007). The Consort Statement on Observational Studies states “Measurement error and misclassification of exposures or outcomes can make it more difficult to detect cause-effect relationships, or may produce spurious relationships” (Vandenbroucke et al., 2007, p.813). In order to facilitate judicious and responsible utilization of research participants within research studies, the use of effective measurement tools is paramount. The lack of consensus and conflicting research evidence in the use of maternal recall of childhood health events, led to the research study that follows. The following study seeks to illuminate any measurement error and/or misclassification of exposures or outcomes.

Research which explores the accuracy and consistency of measurement methods is necessary, namely validity and reliability, which is at the core of the study to be undertaken. The need to assess the extent to which measurement tools utilized are in fact capturing the information they are intended to, in a consistent manner when repeated over time, is integral to effective scientific enquiry. Validity is described as “An estimate of the accuracy of an instrument” (Peat, Mellis, Williams, & Xuan, 2002, p.105). It is concerned with whether a measurement tool actually measures what it set

out too, what it is purports to measure. An estimate that is proved to have little systematic error or little bias can be described as 'valid', by being found to measure what it intended (Rothman, Greenland, & Lash, 2008; Sechrest, 2005).

Whereas reliability is concerned with the reproducibility of results found using a measurement tool over time, or when someone else is using the measurement tool for the same purpose. If a measurement tool is reliable it can be said to have consistency and dependability, when applied in different situations and at different times, assuming it is measuring the same thing. However a measurement tool can be shown to be reliable but infact produce consistent results initially appearing to be accurate, until one explores if it is actually measuring what it purposes too. An unreliable measurement tool can lead to random errors in measurements undertaken, through producing imprecise measurements. Assessing both is obviously crucial to investigate if you are obtaining good quality data and undertaking research in a responsible manner, striving to improve measurement procedures (Koepsell & Weiss, 2003; Fleiss, 1981).

1.3 Statement of Purpose

1.3.1 The context for the study

The Pacific Islands Families (PIF Study) birth cohort study seeks to undertake research that is both methodologically robust and culturally sound, investigating issues that have theoretical and scientific importance to Pacific people resident in New Zealand (Paterson et al., 2006). Critical in eliciting, reporting and acting on evidence is that the information is valid and reliable. Otherwise, findings and subsequent recommendations may be erroneous, resources wasted, and mis-represent the Pacific populations - all carrying their own heavy ethical implications. The following sub studies within the cohort raised questions about the efficacy of using maternal recall in the measurement of childhood injuires and led to the need for the following study.

A PIF sub-study on morbidity of childhood injuries from birth to two years of age, identified results that indicated the need for further investigation into associations between maternal reported incidence of childhood injuries and the socio demographic variables that appeared to significantly impact on the children's injury rates. Findings indicated a statistically significant level of risk for childhood injury for males ($P=0.01$) and older infants ($P<0.001$). Children born to Pacific Island fathers and non Pacific Island mothers were found to be at a greater risk of suffering an injury ($P<0.001$). The study also found an increased risk in higher or unknown income

groups ($P=0.01$). While the significance of injuries to boys and older children had been demonstrated before, further study was deemed necessary to explore potential confounding factors in the relationship between children born to Pacific Island fathers and non Pacific Island mothers, and higher or unknown income groups to ascertain the precise mechanism for this association (Schluter et al., 2006).

A further PIF Study explored mothers' experience of Intimate partner violence (IPV) and children's subsequent attendance at general practitioners (GPs) or hospitals for injury related events. The study found no significant association between children's hospital ($P=0.77$) or GP attendance ($P=0.91$) for injury and maternal victimization of IPV, over three categories: no physical IPV, minor physical IPV, or severe physical IPV. The null findings were inconsistent with previous findings and responder bias may have occurred. The authors advocated review of medical records to investigate potential under reporting by the maternal self reporting, which was also encouraged by external reviewers, to establish if the null findings could be attributable to responder bias (Schluter & Paterson, 2009).

1.3.2 State research question

The research seeks to review if measurement error is likely to have occurred by the use of maternal recall to elicit information on childhood injuries within the PIF Study. PIF Study reported child injury events will be compared to corresponding listed child injury events contained in the National Health Index (NHI) database, to glean information from both the National Medical Discharge Summary (NMDS), which houses hospital discharge information, and the National Non Admitted Patient Collection (NNPAC), which houses hospital outpatient attendance (MOH, 2009b: New Zealand Health Information Service (NZHIS), 2010). The NHI database contains a national unique identifier code, commonly referred to as the NHI number, that is linked to each New Zealand citizen. It includes basic demographic information that enables a record to be kept of health service provisions linked to individuals in various health related database collections in New Zealand, overseen by the NZHIS and the MOH (NZHIS, 2010).

1.3.3 Study aims

The original primary aim of the study is to examine the validity and reliability of the use of maternal recall in accounting for childhood injuries, by the NHI database acting as the criterion measure or gold standard on which to compare the PIF reported

childhood injuries. The original secondary aim seeks to identify any levels of differential recall within the following socio demographic variables: maternal age, child sex, levels of physical punishment of child, maternal depression, mothers ethnicity, mothers highest educational qualification, English fluency of mother, years lived in New Zealand, alcohol/drug use, household income level, number of household residents, level of IPV, smoking status, employment status, and the mothers marital status.

1.4 Significance of Research

Conducting and publishing validity/reliability studies is important for the quality of the PIF Study findings. Such studies also influence the future direction of data collection of injury observational studies locally, nationally and internationally. The majority of such studies typically have small sample sizes, are cross-sectional and cannot establish potentially important age effects or time changes.

1.4.1 Potential benefits to childhood research

Information gained through this research is important to ensure the PIF Study employ the most effective measurement tools in eliciting information from the PIF Study participants, ultimately seeking to enhance the accuracy and quality of the PIF Study findings. It is crucial to ensure the PIF Study findings are based on the most accurate data and the study seeks to review if maternal recall facilitated this. Given that a number of the PIF Study child and family health and wellbeing assessments are measured through the use of maternal recall, the results of this study has implications not just in the measurement of the child injury information but in many facets of the assessment of the children and their families.

If the study finds that maternal recall is not accurate, consideration on how to ensure the measurements undertaken can more effectively elicit accurate information, can be undertaken. It seeks to ascertain whether maternal injury recall is biased, whether there are systematic or time-dependences in any biases, and whether recall is valid. The results will enhance knowledge in an under researched area of both the use of maternal recall in childhood injuries and the particular characteristics of those to which it may not elicit the most accurate responses. The study will attempt to unravel influences that contribute to accurate information being available. As a recent MOH report states “Any attempt to provide as complete a picture of Pacific child health in New Zealand will expose information and evidence gaps that need to be addressed” (2008c, p.3).

This study seeks to enhance the knowledge base on Pacific childhood injuries, the factors that impact on these events, and their measurement in New Zealand. It is imperative to gain such information given the nature of inequalities in the presentation of childhood injuries within the Pacific community.

Subsequent benefits could flow on from the potential changes undertaken to research methodologies. If the status quo of using maternal recall using the methods previously undertaken remains, this could include protection of research participants by ensuring their time is not wasted by the use of inappropriate measurements and to influence and facilitate the most cost-effective use of resources. This in the long term may lead to more equitable services to vulnerable populations where inequalities already exist. If the study shows the maternal recall is accurate it would add to the existing evidence advocating such an approach to data collection. Therefore subsequently adding to the empowerment of woman/parent's in their ability to engage in a meaningful manner in research that seeks to enhance children's health. If not it may encourage future research projects to explore how measurement tools and procedures can be enhanced to elicit more accurate data, with the aim of leading to improvements in the reliability and validity of data obtained through maternal recall of childhood injuries and other childhood health issues.

1.4.2 Study delimitations

The study focuses on Pacific Island children born at Middlemore Hospital whose mothers consented to their participation in the PIF Study, and who meet the eligibility criteria. Injury data reviewed covers the period 0-6 years of age, with the last date for inclusion of injury event being the day prior to the 6-year interview. No formal examinations will be undertaken of the age effects across the measurement waves, due to the time constraints imposed by this Masters study. However such a formal investigation would be invaluable for future research. Although consideration will be given to the time differential between the amount of nights spent in hospital listed in the NHI database and the nights reported by the PIF Study participants.

The NHI databases cover mainly New Zealand public hospital attendances and correspondingly outpatient clinics under the District Health Boards' (DHB's) jurisdiction. A collection of information is held on publicly funded private hospital treatments, although this is usually reserved for geriatric or maternity service provision, so is not included in the information received from the NHI database. Subsequently

medical attendance at private facilities (including private hospitals and private outpatient clinics/specialist visits) cannot be examined in this study. However due to the high cost of private medical insurance in New Zealand it is unlikely those participants with limited income would find it an affordable option. The exception to this would be the provision of health insurance through employers for family use (not commonly practised in NZ). Injury events that occur outside of New Zealand are unable to be accounted for in the NHI dataset (MOH, 2009c) and therefore bias of data can therefore not be ruled out. The NNPAAC database commenced in July 2006, so all outpatient attendances are only available after this time. Prior to this time period and in fact after as well the NMDS captures some outpatient visits, with more than 3 hour's treatment time being deemed to constitute an inpatient admission. Although this practice is not uniformly undertaken in New Zealand, hence some outpatient events that fall within this definition may be captured in the NMDS database (MOH, 2009b; New Zealand Child and Youth Epidemiology Service (NZCYES), 2008).

1.5 Thesis Structure Chapter Overview

This thesis is comprised of six chapters, commencing with the current introductory chapter. Following this overview of the study and the necessity for the research, Chapter 2 reviews literature on childhood injury, in doing so providing a foundation for the basis of the research to be undertaken. It seeks to identify risk factors and in doing so to illuminate influences that impact on childhood injury rates, and the inherent inequalities that exist in the realm of childhood injuries. A review of current measurement procedures used in injury research will be undertaken, in relation to techniques used, and crucially the inherent challenges that these methods pose. Finally empirical research validity and reliability studies involving both mothers and children from conception to early childhood will be reviewed, including studies that focus on mother's proxy reporting of medical events in comparison to medical attendance records.

Chapter 3 provides information on the context of the study, within the PIF cohort study and provides a rationale and justification for the quantitative and ethical approaches to be undertaken. In-depth information on the procedures used to obtain the secondary data and the linking of the data from the two measurement sources are outlined. A description of the differing measurement tools used is presented. The injury matching variables created to compare and analyse the medical attendance injury events from the PIF Study questionnaires and the NHI database, will then be discussed.

Finally explanation and justification of the statistical analyses to be undertaken will be provided.

Chapter 4 depicts key findings of the research, with descriptive and analytical analyses undertaken. Specific focus on the characteristics of the injury events captured and the nuances of combining the data sets will be presented in order to illuminate potential reasons for the data not matching, to form the basis for the discussion in the following chapter. Chapter 5 seeks to present a thought provoking critique of the results by combining the findings with previous research, and the research questions on which the study is based. Acknowledgement of the complexities and challenges of undertaking such research will be discussed along with the corresponding limitations imposed by the inherent procedures. Chapter 6 concludes the thesis by providing an overall summary of the study and resulting implications for future research in this field, both in terms of protocols and the limitations that such research presents. Auxiliary information to support the information presented will be included as appendices, rather than in the main text of the chapters.

2: Literature Review

2.1 Introduction

This chapter commences with Section 2.2 identifying the burden of childhood injury within the international and local New Zealand context. An overview of some of the unique and diverse characteristics that are manifested within the many ethnic groups that encompass Pacific peoples residing in New Zealand is discussed. Identification of the presentation of childhood injury in New Zealand follows, with particular focus on childhood injuries for Pacific Island children. Section 2.3 reviews the wider social determinants embedded within the families, communities and societies in which children live and play which impact on child injury rates. The resulting inequalities and associated risk factors that lie within child injury statistics are reviewed.

Crucial to identifying these risk factors and how the environment impacts on inequalities in childhood injury rates is how childhood injuries and the influential factors which effect injury are measured. In section 2.4 the measurement techniques utilized in childhood injury research are reviewed and critiqued in relation to their respective strengths and limitations. The impact of measurement error on the measurement of childhood injury is discussed, along with the crucial role that validity and reliability studies play in seeking to ensure measurements of childhood injury undertaken are as accurate and precise as possible.

Section 2.5 presents research findings on maternal and proxy recall of maternal and childhood health events, including childhood injuries. Reliability and validity studies that sought to establish the concordance between maternal/proxy report of child health events and medical records/registration records will be critiqued. These critiques, together with the previous information, seek to identify gaps in the current knowledge base, along with conflicting findings to provide the context and rationale for the preceding study. Finally section 2.6 concludes with an overall summary of evidence presented.

A wide range of literature was consulted to identify relevant information on child injury. Computer searches were undertaken in the following databases: SCOPUS, PsychInfo, Web of Science, and Medline. Key search words included; ‘injuries’ or ‘injury’, ‘child’ or ‘childhood’, ‘recall’ or ‘recall bias’ or ‘bias’, ‘maternal reporting’ or

‘maternal recall’, ‘validity’, ‘reliability’, ‘proxy’ or ‘proxy respondent’, ‘measurement’ ‘parent’ or ‘parent report’, ‘self report’, ‘agreement’, ‘concordance’, ‘health care utilization’, ‘accuracy’, and ‘remember’. Search dates were kept open due to the dearth of reliability and validity studies exploring the concordance between maternal recall of childhood injuries and the corresponding medical records for the childhood injury events. The search was limited to English articles.

2.2 Childhood Injury

2.2.1 The burden of childhood injury

The identification of childhood injuries as one of the leading causes of morbidity and mortality in children internationally, only just begins to reveal the true extent of the burden of childhood injuries that result for children, their families, and society. It is widely acknowledged that injuries we know about are in fact the ‘tip of the iceberg’, many injury events never come to the attention of health providers. The WHO states that no overall global data is available on the cost of childhood unintentional injuries (WHO, 2008). New Zealand data available revealed the Accident Compensation Corporations (ACC), a Crown organisation providing support for individuals with injuries, average ACC cost injury claims per annum alone for children during 2003-2008 time period was \$117.2 million. Of significance is the staggering cost in the 2007-2008 time periods where a total of \$146.6 million was spent on childhood injuries (Alatini, 2009).

While the treatment cost of injuries can be calculated, the unseen and often higher costs to the child, their family and community remain unquantified. Tremblay and Peterson (1999) stated “Economics fail utterly to capture the human suffering that result from serious injury and bereavement” (p. 416). The potential flow on effects from injuries vary depending on the extent and consequences of the injury, and include: psychological trauma to the family, potential loss of the future, and extra child and family stress, both financial and emotional (Miller, Romano, & Spicer, 2000). The potential for injuries to quickly take away the future or alter it through resulting disabilities and hardship is a very real possibility. Early childhood injuries can impact on child development, the effects of which can have lasting effects on the children’s future potential (Jaspers, de Meer, Verhulst, Ormel, & Reijneveld, 2010). For some communities these potential losses are magnified due to pre-existing inequalities that

exist, both in terms of health, but also enmeshed within their social economic environment. Pacific Island children are one such group.

2.2.2 Characteristics of Pacific peoples in New Zealand

The 2006 New Zealand Census of Population and Dwelling found 265,974 (6.9%) of New Zealand residents identified as belonging to a Pacific ethnic group (Statistics New Zealand, 2007). These Pacific ethnic groups are non homogenous in nature and the groups represented in New Zealand include: Samoan, Cook Island Maori, Tongan, Niuean, Fijian, Tokelauan, Tuvalu, and others. The Pacific population is identified to be youthful in nature, with the overall median age for a New Zealander being 36-years of age, while in the Pacific community the median age is 21-years of age. The median age of a New Zealand born Pacific person is 13-years of age, while the median age for an overseas born Pacific person is 39-years of age. In 2006, 38% of the Pacific population was accounted for by children 15-years of age and under, of which 81% were born in New Zealand. The process of acculturation and integration of Pacific peoples within New Zealand society has resulted in a growing trend for Pacific people to identify with more than one ethnicity, in the 2006 census 70% of Pacific people identified themselves solely within a Pacific ethnic group, whereas previously in 1991 this figure had been 80% (Statistics New Zealand, 2007; Statistics New Zealand & Ministry of Pacific Island Affairs, 2010).

A recent update of New Zealand's population has projected the Pacific population will reach 480,000 by 2026. The number of Pacific children is projected to increase from 110,000 in 2006 to 165,000 in 2026; consequently children from Pacific ethnic groups are predicted to total 17.7% of the ethnic composition of New Zealand children, an increase from 12.4% in 2006. Presently in approximately 25% of all births in New Zealand where the child is identified as being from a Pacific Island ethnic group, the mother is identified as being non Pacific and the father as Pacific (Statistics New Zealand, 2010; Statistics New Zealand & Ministry of Pacific Island Affairs, 2010). In the PIF Study on childhood injuries mothers reports identified non Pacific mothers as having a significantly higher risk of injury ($P < 0.001$) for children under 2-years of age (Schluter et al., 2006). With the projected growth in Pacific births, it is likely that these numbers will increase accordingly, so further investigation into the potential reasons for such a significant higher risk is warranted.

Each Pacific ethnic community have their own distinct heritage and political system, with traditions and protocols, languages, and health beliefs. Despite such recognized diversity, common cultural values and practices that encompass a Pacific world view are shared within the respective Pacific ethnic communities. These include being of a collectivist culture with a strong sense of kinship and affinity to both immediate, extended family and the community at large. Family life is central and integral to society, with shared responsibilities associated with fostering collective health and wellbeing (NZCYES, 2008; Tiatia & Folaki, 2005). A respect for oral tradition prevails, by which collaborative learning is facilitated, and is identified as the preferred method of engagement over written communication (Anae, Coxon, Mara, Wendt-Samu, & Finau, 2001; Health Research Council, 2005). Furthermore spirituality and religion plays a central role in many people's life (Jansen & Sorenson, 2002; NZCYES, 2008).

With such ethnic diversity there are obvious challenges in undertaking research of Pacific peoples within their respective communities. In seeking to uphold research principles and practices, careful consideration of the need to provide balance between these differences and scientific ideals is imperative in any research undertaken. McMurray (2003) provides a rich description of the impact of culture "cultural groups are bound together by a tapestry of historically inherited ideas, beliefs, values, knowledge and traditions, art, customs, habits, language, roles, rules and shared meanings about the world" (p.310). One can see how culture might impact on people's health and wellbeing in a multi-faceted and powerful manner. To ignore or detract from the implications of culture on health could be perceived as ignoring the very essence of an individual and their community. Hence thoughtful consideration is integral when undertaking research of health issues within communities of diverse cultural ideologies such as the Pacific population in New Zealand. This includes identifying the most effective and culturally acceptable manner in which one seeks to measure health and wellbeing, within families and their respective communities.

Associated within these world views are common core values that include humility, interdependence; co-operation; collective responsibilities; reciprocity; and to show dignity and respect for others, particularly those seen in leadership roles or in authoritative positions in the community (Anae, Coxon, Mara, Wendt-Samu, & Finau, 2001; NZCYES, 2008; Tiatia & Folaki, 2005). Pacific people perceive illness and illness symptoms differently from the Western medical systems focus of illness

categorized in 'biological terms'. Pacific concepts around health are multi-faceted, holistic and encompass spiritual dimensions (Finau, 2000; Jansen & Sorenson, 2002). However once again the diversity of the Pacific community is impacted on by the degree of acculturation present as immigrants and their respective generations settle and adapt to New Zealand society, with varying acceptance and integration of traditional beliefs and practices into their daily lives over time (NZCYES, 2008; Tiatia & Folaki, 2005).

The value of Pacific children to their parents, families and communities is embedded within the collective cultural values that prevail, both within recent immigrants and subsequent generations within New Zealand (NZCYES, 2008). Finau (1994) characterises the sheer scale of children's importance to Pacific people and their integral link to both the communities future and present with the words

Children are more than the object of their parent's attention and love; they are also a biological and social necessity. Children are human investments to perpetuate the Pacific; culture, religious and national groups transmit their values through children; individuals pass their genetic and social heritage through children. Ultimately, children are our hope for the continuity of humanity. (p. 52)

2.2.3 Childhood injuries in New Zealand and the impact on Pacific Island children

A recent review of New Zealand morbidity data from 1998-2002 found injury to be the leading cause of death in New Zealand for those aged 1-34 years of age. The percentage of childhood deaths caused by injury in each age group, in comparison to non injury deaths in the following age groups were as follows: 1-4-years (38%), 5-9-years (40.5%), and 10-14-years (44%), all with injury being the leading cause of death in the respective age groups. For children aged under <1-year death due to injury is the fourth largest cause of death and accounts for 4.9% of deaths in this age group (Injury Prevention Research Unit, 2007). In the four years between 2001 and 2005 the New Zealand child injury death rate was 11.1 children per 100,000. In relation to Pacific children on average eight children died per annum from unintentional injuries over this time period. The three leading causes of Pacific childhood injury deaths in New Zealand are suffocation (difficulty in distinguishing accidental deaths from Sudden Unexplained Death Syndrome (SUDS) must be taken into consideration with this cause), drowning

and ‘other specified injuries’. Deaths caused by ‘other specified injuries’ accounted for 50% of all these deaths (Safekids, 2010).

When the overall picture of the impact of childhood injuries is reviewed the significant impact on Pacific children is evident. During the time period of 2003-2007 there were 58,761 (97.8%) hospital admissions for unintentional injuries and 1,323 (2.2%) for intentional injuries for New Zealand children aged 0-14-years of age (Alatani, 2009). Of which 10.7% of all unintentional childhood injury admissions in New Zealand were for Pacific children (Safekids, 2010). On average during this time period 901 Pacific children were hospitalised each year for injuries, on average 2.5 children per day (Alatani, 2009).

Table 2.1 shows the types of injuries where Pacific children aged 0-14-years of age, were identified to be at a significantly higher risk for hospital admission, than for either Maori, European or Asian children in the time period 2003-2007; and the types of injuries where they are identified as being at lower risk in comparison to Maori and European children, although they were at higher risk than Asian children (Alatani, 2009).

Table 2.1; Risk factors for hospital admission for injuries in 0-14-years old Pacific children resident in New Zealand 2003 – 2007.

Variable	Rate/100,000	Rate Ratio (RR) Compared to European	(95% CI)
Electricity/Fire/Burns	91.5	2.55	(2.25,2.89)
Unintentional non-transport injuries	1,355.8	1.26	(1.22,1.30)
Inanimate mechanical forces	528.6	1.89	(1.80,1.99)
‘Other causes’	74.8	1.11	(0.98,1.26)
Pedestrian injuries	50.8	2.87	(2.42,3.41)
Accidental poisoning	41.4	0.58	(0.49,0.68)
Cyclist	57.8	0.67	(0.58, 0.77)
Land transport injuries	151.5	0.72	(0.66 ,0.78)

Note: Source – Alatani, 2009, Safekids New Zealand; Numerator – National Minimum Dataset; Denominator-Census.

Rate ratios (RR) are unadjusted; Rate is 100, 000 per year; with RR 1.00 for European children used for the comparison group.

2.3 The Social Determinants of Health and Child Characteristics that Impact on Injury Risk

Inequities in health arise due to the different circumstances that impact on people’s lives and subsequently their health and wellbeing, which are commonly referred to as the ‘social determinants of health’ (Wilkinson & Marmott, 2003) These encompass a range of social, economic, cultural and political factors that influence individual and community health. Dahlgren and Whitehead’s (1991) widely used socio-ecological model of health clearly illustrates the multitude of influences that can impact on the health of an individual. Individuals commence life with a genetic makeup that impacts on their health, but other external influences are known to have profound effects on their eventual health and wellbeing. These include characteristics of their family, physical, social, and community environments, including living and working

conditions. These characteristics, in turn, are impacted on by macro level policies that provide the framework on which society functions and ultimately can promote equity in health or increase inequalities among disadvantaged peoples. One can clearly see that most of these areas fall outside of immediate influence of the health sectors.

An overview of literature identifies key characteristics of children, their parents and families, and the communities in which they live that put them at increased risk of experiencing an injury. Injury types are often characterized by a combination of risk and protective factors. Although once again studies show conflicting findings, a general overview will be given of commonly found risks, rather than a critique of research findings. The causes of and influences of injuries are multi-faceted and are also shown to reflect the environment in which the child and their families live, work and play. Not just within the family, but wider out into the local community, and society itself. Jaspers et al., (2010) highlight the stark differences in potential outcomes for some children with illuminating phrases in reflecting that childhood can be seen as a “window of opportunity” or a “window of vulnerability” (p. 185). These differing ‘windows’ have a profound impact on the inequalities that are seen in society and indeed within the child injury rates.

2.3.1 The family

A gradient between poor health and increasing levels of deprivation is well acknowledged, not just within people with lower socioeconomic status (SES), but across all levels of the social ladder (MOH, 2009a; National Health Committee, 1998; Wilkinson & Marmott, 2003). A view of some of the socioeconomic conditions that are familiar for many Pacific peoples sheds some light on the potential influences for the over representation of Pacific children in some areas of childhood injuries. A 2008 report on child poverty in New Zealand, commissioned for the Children’s Commissioner identified that 40% of other and Pacific children were likely to be considered to live in poverty. Poverty was defined by families having < 60% of their total median income left after housing costs over the time period of 2003 to 2004 (Fletcher & Dwyer, 2008).

The 2008 Living Standards Survey, undertaken for the Ministry of Social Development, found Maori and Pacific people have hardship rates two to three times higher than European or other ethnic groups (2009). Of great concern is that the median income for a person of Pacific ethnicity in 2006 census was \$20,500, in comparison to

\$24,400 for the New Zealand overall rate. In the 2006 census Pacific children were found to be significantly more likely to live in NZ(New Zealand) Deprivation Index Deciles 9-10 (which are the areas of highest deprivation in New Zealand), than non Pacific children. The 2006 census found that only 22% of Pacific people owned their own homes, in comparison to 53% of the total New Zealand population. At the time of the 2001 census 42% of Pacific peoples were found to live in the NZ Deprivation Index Decile 9-10 areas, in comparison to 10% of the general population (MOH, 2008c).

The impact of socioeconomic status is clearly reflected in hospital admission statistics for childhood injuries, with children from Decile 9-10 areas admitted more frequently than any other SES group in New Zealand (Alatini, 2009; The Children's Social Health Monitor, 2009). The increased risk of injury to children is in concordance with both New Zealand and international research which found an increased risk of injury to children living in socially disadvantaged circumstances (Avery, Vaudin, & Fletcher, 1990; Faelker, Pickett, & Briston, 2000). D'Souza, Blakely, and Woodward (2008) estimated that if poverty was eliminated from deaths due to child injury, as a risk factor, the mortality rate may fall by 3.3% to 6.6% in New Zealand. Some of many parental characteristics that also have been found to impact on children's injury levels include: substance use (Damashek, Williams, Sher, & Peterson, 2009), maternal characteristics include maternal age (Kendrick, Mulvany, Burton, & Watson, 2005; Towner, Dowswell, Erington, Burkes, & Towner, 2005), and maternal depressive symptoms (Schwebel & Brezaussek, 2008).

2.3.2 The environment

The case of pedestrian injury events illustrates potential reasons as to why Pacific children are over represented in this area, when one considers the links between the multi-faceted impacts of social determinants. A retrospective review of pedestrian driveway injuries in the Auckland region, between November and December 2001 was undertaken and revealed of 93 children involved in pedestrian injuries, 43% were Pacific children (Hsiao et al., 2009). Children aged 0-4 were overrepresented in the figures, being involved in 73% of the events. Overall 80% of the pedestrian injury events occurred in the child's home driveway (often shared by multiple houses), in which 51% of these homes were rental properties, while only 13% of the driveways were fenced off from the house. Of particular concern was that 57% of the rental properties were found to be owned by Housing Corporation New Zealand, a government housing agency. There are obviously multiple contributing factors to why a child is involved in such an

incident including the supervision of the child, the physical environment, and the cognitive ability of a child to problem solve avoiding such an incident. One could argue that these incidents are not solely caused by the child or their families, and multiple agencies and individuals can contribute to making the home and community environments safer for children. International research has again demonstrated a link between social disadvantage and the environment in which children live which increase their injury risk (Kendrick et al., 2005).

2.3.3 The child

Inherent risk factors identified for children, either being genetic or psychological or physical include; gender, boys are more at risk of injury (Kohen, Soubhi, & Raina, 2000; WHO & UNICEF, 2008); with progressing age the levels and types of injuries alter corresponding to developmental changes (Towner et al., 2005; Kohen, Soubhi, & Raina, 2000); disabled children are at increased risk of injury (Towner et al., 2005; WHO & UNICEF, 2008); and child behavioural temperament and psychosocial abilities have been found to impact on injury rates (Schwebel & Gaines, 2007). While these and the preceding sections have reviewed some risk factors there are many more, which reveal the truly complex web of factors that can culminate in an injury to a child.

2.4 Measurement Methods

How to obtain the most accurate data on childhood injuries could be said to be as complex as the factors that contribute to the rates of childhood injuries. Epidemiologists and health clinicians alike rely on accurate information from mothers to both diagnose and undertake research into all child health issues. The irony of this fact is that considering the negativity that at times surrounds the use of maternal recall, it contributes significantly to the medical diagnosis itself, to which maternal reports of child health are compared in validation studies. The use of ‘self report’ and ‘proxy respondent’ at times appears to be used interchangeably in the literature. In relation to health research, mothers in answering child health questionnaires will often report on their own health or socio-demographic characteristics, as well as acting as a proxy respondent on behalf of their children to report their health and medical attendance. Concern about the use of ‘self or proxy’ reporting is frequently expressed, often viewing its use as appropriate when other sources are not practical. It is often viewed as a measurement option in which information is not captured in the ‘most judicious manner’ (Neugebauer & Ng, 1990; Toon, 2000).

Factors that impact on such reporting are shown to vary depending on both the characteristics of the research participants, and the research protocols and procedures that are undertaken. Multiple factors combine to influence the level of recall bias that may be present. Coughlin (2006) identifies five main influences including: time interval since exposure, personal characteristics (memory, motivation, educational level, and health literacy level), significance of the event, interviewing techniques used, and the impact of social desirability bias. Social desirability bias can impact on individuals answering of questions, by them either consciously or unconsciously giving an inaccurate response to a question, dependent on the perceived social norms that they feel they should meet in a given situation. The impact of cultural norms and societal expectations is at play, with an obvious need to ensure the completion of research questionnaires is undertaken in the most conducive circumstances to seek to alleviate or minimize such responses (Fisher & Katz, 2000).

There is a need for compromise between the ideal scientific endeavour and the realities of undertaking research, not just in a practical resource sense. But equally so by having assessment methods that are acceptable and culturally salient to individuals, which is imperative to gain their support for research. Differing world views and levels of health literacy among different communities and individuals require adjustments to be made to measuring tools, to ensure they do capture what they intend too (Warnecke et al., 1997). It could be argued that this is not a compromise but a necessity. Proxy/self reporting of parental practices and child health is practical, enlightening and necessary given the developmental levels of young children (WHO & UNICEF, 2008).

Refinement of measurement tools is undertaken in an effort to enhance the recall of research participants by the use of cues, questionnaire development, and protocols that increase the likelihood that accurate responses will be obtained (Schwartz, 1999; Warnecke et al., 1997). Ensuring measurement tools are as rigorous as possible is advocated to avoid the potential for recall bias to adversely affect study findings, through misclassification (Mickalide, 1997; WHO, 1996). Obtaining information from multiple sources is advocated, in order to account for the inherent strengths and weaknesses that are present in all measurement methods (Del Boca & Noll, 2000).

In the case of childhood injury it is crucial to correctly distinguish an injury event from a non injury event. This facilitates researchers and policy makers to build a realistic picture of injury and the associated socio-demographic factors that impact on

its presentation. Whilst acknowledgement is given to the potential for bias existing in maternal proxy reporting, other forms of injury measurement have been shown to be less than perfect also (Cummings, Koepsell, & Mueller, 1995). The use of information from medical records has been one of the few alternate sources of health information, prior to the advent of electronic databases. But as one will see in the following reviews of proxy studies the information contained is often incomplete (Tate, Dezateux, Cole, Davidson, & the Millennium Cohort Study Child Health Group, 2005; Quigley, Hockley, & Davidson, 2007).

Electronic databases themselves rely on the information gained to be entered into the system, after a variety of processes are undertaken that can impact on the data accuracy. O'Malley, Cook, Wildes, Hurdle, and Aston (2005) provide a thorough overview of factors that impact on the 'end product' or ICD coding of medical events that is eventually recorded into any database. These range from: processes on presentation, the quantity and quality of communication that takes place, and the physician's skill level and diligence in completing medical records adequately and in a legible manner. The person who is responsible for coding the medical information into the dataset is likewise going to be impacted on by their own skill level, and the coding processes undertaken to designate an appropriate International Classification of Disease (ICD) code. Obviously transcription errors and lack of attention to detail can occur at any step along the way. One can see ultimately many of these factors would also impact on how accurately a parent will be able to recall medical attendance events in detail as well.

2.5 Previous Studies and Evidence of Differential Recall by Proxy Reporters

A review of literature reveals not only disparities between research findings of the level of concordance between maternal reports and medical records, but also differences in the methodological approaches undertaken which are likely to impact on the accuracy of these findings. This section includes a wide range of studies relating to mothers and their children. A conspicuous absence of studies focusing on mother's recall of childhood injuries was found when reviewing the literature. Subsequently a wide range of other studies pertaining to motherhood, including pregnancy, birth and postnatal activities, infant care and health care utilisation have also been reviewed. This wide range was undertaken in an endeavour to illuminate recall and factors that have

been found to impact on recall, that are apparent during the period of early motherhood and beyond.

2.5.1 Maternal recall of pregnancy and birth related studies

Rice et al. (2007) sampled 126 mothers that had previously attended UK fertility clinics in order to conceive a child, and was undertaken 4-9-years post delivery. The study examined recall for a variety of pregnancy and delivery related events including: self reported information on smoking and alcohol use during pregnancy, preadmissions prior to birth, birth mode of delivery, and the birth weight of the baby. The recalled events were then compared against medical records to assess concordance. A kappa value of $\kappa = 0.17$ was found for alcohol use during pregnancy, with other variables ranging from fair to very good using Landis & Koch's characterisation of kappa values. Landis and Koch's (1977) commonly cited characterisation is used to represent the levels of agreement beyond chance; $\kappa < 0.00$ was taken to indicate poor agreement; $\kappa = 0.00-0.20$ slight agreement; $\kappa = 0.21-0.40$ fair agreement; $\kappa = 0.41-0.60$ moderate agreement; $0.61-0.80$ substantial agreement; and $0.81-1.00$ was taken to represent almost perfect agreement beyond chance.

Maternal characteristics were not found to impact on the agreement levels, with the exception of recall of smoking during pregnancy which was recalled less accurately by mothers with higher SES levels, $\kappa = 0.47$, compared to $\kappa = 0.89$ ($P=0.001$). This suggests social desirability bias may have impacted on the recall of smoking for higher SES woman. Further limitations included the potential for highlighted recall due to the mothers obtaining fertility care in order to conceive. The potential for measurement bias was present as mothers could have consulted information on their pregnancy and birth/child characteristics from records held at home (Rice et al., 2007).

An American study of recall of childbirth events was undertaken with an ethnically diverse sample of 277 woman, whose mean age at questionnaire was 27-years (range; 15-53-years), with a median time period since delivery of 10-weeks (range; 0-21-years) (Elkadry, Kenton, White, Creech, & Brubaker, 2003). The mean age at delivery was 26-years (range; 15-42-weeks). The findings showed that 60% of mothers had imperfect recall of childbirth events, in comparison to the events in the medical records, for at least one major labour event. A multivariate logistic regression model was used for the prediction of ≥ 1 incorrect responses and found the significance of impact on recall to be ($P=0.004$) for ethnicity, ($P=0.01$) for parity (with each extra child

a 37% reduction in the odds of recalling events accurately was found), and ($P < 0.001$) for years since delivery (Elkadry et al., 2003).

The United Kingdom (UK) Millennium cohort study of children linked recall of birth weight at 9-months post delivery, for 11,890 children with birth registry data (Tate et al., 2005). Overall 92% of mothers accurately recalled the birth weight within 100 grams. But once again variation was apparent across different ethnic groups. A multivariate logistic regression model was used for the prediction of incorrect responses. It found the significance of impact on recall to be: ($P < 0.001$) for first born baby, ($P < 0.001$) for non English languages spoken at home, ($P < 0.001$) for mother's ethnic group, and (no P value stated) for women not born in the country. It was posited that women giving birth to a first child would be less familiar with medical terminology, which would also be compounded for those with English as a second language. Limitations included concern at the extent of discrepancies in the birth registration data, with subsequently only 64% of the cohort children records being available for inclusion in the sample. Of note was the inability to estimate the birth records reliability, as there was no way to know if the birth weights were recorded accurately in the first place. A review of the data found that 27% of the discrepancies in weight may have been due to transcription or rounding errors, on behalf of the mothers (Tate et al., 2005). This phenomenon was also observed in a study of birth weight in Taiwan (Li, Wei, Lu, Chuang, and Sung, 2006).

Data from a Taiwanese nested case-control study of diabetes and birth weight in 3 million school children aged between 1-12-years that were screened for diabetes's, was used to investigate recall of birth weight. A sub-sample of 1,432 mothers were interviewed by telephone at which time the birth weight was elicited and then compared to the recorded birth registry data. The birth weights were categorized into eight different levels to assist analysis. Exact agreement levels were found to be as low as 15.9% , but this low level of concordance increased to as high as 65.6%, if different weight levels were accepted as a match, by allowing a difference of up to 500 grams extra weight. Li et al. (2006) identified the mothers had a propensity to round off their child's birth weight to the next highest round number.

Mothers with lower family income levels had higher rates of agreement (16.1%-16.7%) and lower over report rates (60.8%- 64.1%), in comparison to more affluent mothers whose rates of agreements ranged from (10.7% – 13.3%), with over report

levels ranging from (64.4% – 76.9%). Other factors that impacted on the level of agreement included children's age at the time of interview ($P < 0.001$) and the birth order of child ($P < 0.001$). A limitation of the study was that no kappa statistics were reported to account for beyond chance agreement between the mothers reporting of birth weight and the birth certificate information (Li et al., 2006).

2.5.2 Health care visits

The Washington District of Columbia, community based randomized controlled trial (RCT) parenting programme, the Pride in Parenting study, of low income mothers aged >18-years, with newborn infants who had received little or no prenatal care, compared mothers reports of health care utilization to their medical records (Kennan, El-Mohandes, El-Khorazaty, & Michele, 2007). A total of 286 mothers initially enrolled at baseline but attrition resulted in only 168 mothers remaining at 12-months. Mothers were interviewed when the children reached 4, 8 and 12-months of age (in a strategic effort to minimize recall bias). Questions focused on GP visits, outpatient clinic (OPC) visits, emergency department (ED) visits, and hospitalizations. The reasons for the visit were also reviewed focusing on if the visit was a 'sick baby' or 'well baby' visit. Reports matched in only 19% of cases, with kappa values ranging from $\kappa = 0.07$ for a Diphtheria immunisation booster to $\kappa = 0.62$ for ED visits. Nearly half of the mothers recorded more doctors visits than were recorded in medical records ($P = 0.017$).

It was found that 47% of mothers over-reported and 34% under-reported the total medical attendance visits that occurred. Interestingly 25% of reported visits by the mothers were not reported by providers. The highest overall level of agreement was found between mothers and providers for the use of EDs. An associated noteworthy finding was that the mothers also recorded significantly less visits to this venue, than were reported in the ED medical records (0.6 versus 0.9, respectively, $P < 0.001$) (Kennan et al., 2007).

A further study assessed the validity of the use of maternal reports of acute hospital and ED health care use for children under 3-years of age. A sample of 2,937 families in the Healthy Steps for Young Children study were reviewed from an overall cohort of 3,737 families (D'Souza-Vazirani, Minkovitz, & Strobino, 2005). These families were invited to participate in telephone interviews at 2-4-months and again at 30 to 33-months (asking participants to review their medical attendance events over the previous 12-months), at which time information was elicited on maternal depressive

symptoms and health care use. Medical records held by local hospitals and emergency clinics (EC) were reviewed by trained medical record abstractors, whose role was to obtain pertinent data from the medical records. This data and the mothers reported information was then used to calculate the proportion of events that agreed, using observed agreement and the kappa statistic was used to assess the beyond chance agreement.

Absolute agreement was high for hospitalizations since birth ($\geq 90\%$) at both interviews, while for ED use a high level was only found at $\geq 90\%$ at 2-4-months only. Kappa values ranged from $\kappa = 0.77$ for hospitalizations since birth, at the 2-4-months interview, to $\kappa = 0.53$ at the 30-33-months interview. The kappa values were lower for ED visits and ranged from $\kappa = 0.64$ for hospitalizations since birth, at the 2-4-months interview, to $\kappa = 0.41$ at the 30-33-months interview. A disproportionate number of injuries, that were recalled accurately, were stated to have occurred near the time of the interview. No differences were found with parity, income, and presence or absence of maternal depressive symptoms but beyond chance agreement was found to decrease with maternal age < 20 -years and duration of recall. Older mothers were stated to have a recalled hospitalizations more than younger mothers did, but limitations were evident in the study, while observed agreement percentages were provided and kappa statistic was undertaken, no p-values or confidence levels were provided to assess the statistical level of significance found between the mothers reports and the medical records, or for contributing characteristics that were stated to have impacted on the accuracy of the self reporting (D'Souza-Vazirani et al., 2005).

Contrary findings were found in relation to younger mothers levels of recall in a study undertaken by Pless and Pless (1995). Two paediatric practices in Montreal, Canada recruited 288 parents of children aged 1-13-years old, by approaching 438 parents in the practice waiting room. The parents were asked to complete a self administered questionnaire about medical attendance events 'ever' or 'in the last year', for otitis, asthma, bronchitis and 'accidents', in relation to paediatrician visits and hospital attendances. An overall kappa value of $\kappa = 0.19$ was found for recall of accidents in both time periods, and was in fact the lowest kappa value found overall. A kappa value of 0.48 was found for health visits in the past year. The researchers stated mothers responded more accurately than fathers ($P = 0.02$) and recall was more accurate in parents of younger children ($P = 0.02$). No statistical significance was found in relation to the impact of socio-economic status (SES), parity, education or occupation, on recall

levels of agreement. Although the researchers stated that younger mothers recalled events more accurately the youngest age category appeared to be <30 years.

Multiple limitations were evident in this study including non random sampling of participants. Ineligible parents included those who could not read English or French (n=27). Questionnaire completion was undertaken by participants while waiting for an appointment, which may have resulted in an environment of 'rushing' in order to complete the questionnaire in time. Overall 10% failed to complete the questionnaire, due to being called into their appointments. No clarification or definition was given as to what injuries were encompassed under the definition of 'accident', potentially leading to misinterpretation of what answer was required. The final limitation noted was that the paediatrician's medical records were used as the criterion measure to investigate the level of agreement. The accuracy of these records was acknowledged to not always be valid and dependent on reports of hospital visits being provided to the paediatric practices, from hospitals. Obviously all of these factors may have contributed to the accuracy of results found. The study was found to have methodological flaws that bring into question if one could generalize the study findings to the wider population (Pless & Pless, 1995).

Ungar et al. (2007) used data extracted from a health insurance plan and from within the Canadian Institute of Health Information databases. They sought to assess agreement between parents reports of GP visits, ED visits, and hospital admissions for 545 children (parents n=457) with respiratory conditions, aged 1-18-years old. Initially a sample of 879 children were recruited from a completed study on the effects of medication plans on asthmatic children; but only 62% gave permission for medical records to be accessed. The use of the International Classification of Diseases -9CM/10 codes for respiratory conditions were used to extract data from the health information database, to compare these events to the parent's reports. Face to face interviews were conducted and focused on medical attendance events in OPCs over the previous 6- months and within the past year for hospital admissions and emergency department visits.

Slight agreement was found (using Landis and Koch's characterization) for outpatient visits = κ 0.10, ED visits = κ 0.57, and for hospital admissions κ =0.80. Agreement was also reviewed using the kappa statistic for the effects of the education and income levels of parents on agreement levels, and no statistically significant

relationship was found. Kappa values ranged from $\kappa = 0.09$ and $\kappa = 0.14$ for outpatient visits agreement for parents with a low education level and high education level respectively, and the kappa values for low income versus high income for ED visits where $\kappa = 0.52$ and $\kappa = 0.63$ respectively. One limitation of this study is that eligible participants had to be fluent in English to participate (Ungar et al., 2007).

Stone et al. (2006) investigated maternal recall of child unintentional injuries in identified at risk families, in a cross-sectional study using data from a RCT community base home visitation trial in Hawaii. The maternal reporting of childhood injuries of 443 children were compared to the primary care medical record for injury ED visits and hospitalizations. Of the 490 injuries found 48% were reported in the primary care records, 22% by maternal interview, and 30% in both sources. A total of 76% of hospital admissions were recalled. However the agreement between the primary care records and maternal recall overall was fair ($\kappa = 0.47$), with both a significantly greater number of children identified as having had an injury event through medical records than by maternal recall ($P < 0.001$), and the mean number of injuries reported was also higher in the medical records ($P < 0.001$). The researchers acknowledged a limitation in the study was that only the primary care medical records were reviewed, not the actual hospital medical records for ED visits and hospitalizations. They considered that if the hospital records had been reviewed, a higher level of concordance may have been found. The study team encouraged researchers to use more than one source of data to ascertain the level of child injury presentations.

Cummings, Rivara, Thompson, and Reid (2005) study in a Group Health Co-operative in Washington DC, of 1,672 young children aged 6-years and under, used computer based records to review parents reports of injuries, and sought to identify the ratio of recalled injuries. Children were selected that had been recorded as having an injury over the previous year. A random sample of 2,807 children's parents were contacted, of which 494 (17%) declined to participate. Telephone interviews were held, with parents being asked to recall the three most recent treated injuries. The researchers stated little evidence was found to show recall was affected by the child's age, respondents marital status, parity or household income; although recall was found to be more accurate with higher levels of education ($P = 0.02$). Overall parents were found to recall 61% of injuries, when compared with the computerized records, with 80% of major injuries (defined using ICD codes) matching the computer records.

Investigations into the influence of time on the accuracy of recall found the recall ratio at one year after the event to be 0.37 (95% CI 0.32-0.40) from 0.82 (95% CI 0.79 – 0.85) for injuries the day prior to the interview. For minor injuries treated in an ED the recall ratio was 0.77 (95% CI 0.71 to 0.82). Recall was found to decline with time, particularly for minor injuries. The researchers recommended varying recall periods be used in injury research studies depending on the severity of the events and the place of attendance. This included a six month recall period to capture 90% of major injuries; a three month period to capture the same level of minor injuries at hospitals, ED, or urgent care centre; and finally no recommendations were given for minor injuries treated in a clinic due to the fact that even a short recall period may only identify <70% of such events (Cummings et al., 2005).

The finding of injury recall deteriorating with time is in concordance with a study undertaken by Harel et al. (1994) that advocated a 1-3-month recall period was ideal for attaining information on childhood injuries. Data from the 1988 Child Health Supplement to the National Health Interview survey undertaken in the USA, from a sample of 17,110 completed surveys that contained information on multiple health issues, including injuries was used in the analysis. The study sought to assess the effects of using different recall periods on estimating annual injury rates for future health surveys, from the injury information in the surveys. They identified two main forms of potential bias impacting on such recall, namely memory decay due to the loss of information on the event and the ‘telescoping effect’ where events are brought forward closer to the time when questions are asked. They acknowledged concern at finding a sharp fall in estimated annual rates of injuries in children aged 0-4-years over varying time periods. Commencing with 27 per 100 at a 1-month recall period, to a rate of 16 per 100 for a 5-month recall period, which was stated would result in a decline of over 70% by 12 months (Harel et al., 1994).

Common themes emerged in the reviewed studies and their associated publications that included the researcher’s ability to obtain accurate data and generalize from their studies findings. Firstly limitations with the consistency of data in medical records and data registries varied and effectively inhibited larger sample sizes to be utilized in analyses (Tate et al., 2005; Tate, Calderwood, Dezateux, Joshi, & the Millennium Cohort Study Child Health Group, 2006). Evidence also showed that participants who declined to participate in reliability and validity studies were more likely to be from minority ethnic groups and those who reported English as a second

language (Tate et al., 2006; Ungar et al., 2007). Commonly recognised limitations included the capacity for specific and detailed recall to be maintained over lengthy time periods, with the timing of interviews shown to be a crucial factor in the expected accuracy of results (Cummings et al., 2005; Harel et al., 1994). This has obvious implications for the accuracy of recall for the frequent number of studies that utilize a one year recall period in questionnaires or surveys.

2.6 Summary

The evidence is clear that Pacific children are over represented in many types of hospital admissions for childhood injuries in New Zealand. In recognition of the projected growth in the Pacific child population in New Zealand, it is imperative that a greater level of understanding of the factors that impact on these statistics be explored. The PIF cohort study seeks to contribute to the improvement of the health and wellbeing of Pacific children, their families and communities in New Zealand. The study acts accordingly by attaining insights into factors that enhance and inhibit such health and wellbeing. As previously alluded some of the information gained from the PIF Study participants is by retrospective recall.

The evidence presented shows conflicting evidence as to the accuracy and limitation of using retrospective recall, with different socio-demographic factors found to impact on the findings between studies. For example Pless and Pless (1995) found younger maternal age increased the accuracy of recall and conversely in another study D'Souza-Vazirani et al. (2005) found older mothers recalled more accurately. A wide range of kappa values were found over the preceding studies. In the maternal recall of pregnancy and birth related studies the kappa values for concordance between reported medical events and medical records ranged from poor to almost perfect. In exploring the concordance between mothers reports and medical records related to socio-demographic characteristics kappa values ranged from slight to almost perfect, range; $\kappa=0.17$, $\kappa=0.89$ (Rice et al., 2007). Whilst the overall kappa values for type of health care visit event (excluding emergency room visits or hospital admissions) showed variance in the levels of agreement from slight to substantial, range; $\kappa=0.07$, $\kappa=0.47$ (Kennan et al., 2007; Stone et al., 2006). Agreements shown for emergency room visits showed fair to substantial agreement; range $\kappa=0.41$, $\kappa=0.64$ (D'Souza-Vazirani et al., 2005). While agreement for hospital admissions showed moderate to substantial agreement; range $\kappa=0.53$, $\kappa=0.80$ (D'Souza-Vazirani et al., 2005; Ungar et al., 2007).

Conversely the limitations of other measurement methods equally are of concern, and assumptions also are made about their effectiveness, too often with very little evidence showing the accuracy of alternate measurement methods as well. The practical benefits and unique insights that can be gained by interviewing mothers cannot be underestimated. Acknowledgement of the distinct cultural practices and beliefs of Pacific people, when combined with socio-demographic factors such as level of education, years spent in New Zealand and language skills may all impact on their recall of childhood injuries, illnesses and medical attendances. The following study seeks to assess if the use of maternal recall of childhood injuries has in fact been a reliable and valid measurement tool. If not, then it provides an opportunity for change to improve the method of measurements undertaken to gain information and new avenues to pursue in research to improve measurement not just of childhood injuries, but other areas of childhood research as well.

3: Methodology

3.1 Introduction

This chapter will commence with a description of the PIF Study, including an overview of the study design, practices and protocols. Information on the sub-study to be undertaken will then be described in depth.

3.2 The Cohort Study – PIF Study

3.2.1 Study design, population and setting

The PIF Study is a prospective birth cohort study of Pacific Island children who were born at Middlemore Hospital, Manakau City, South Auckland, New Zealand. A consecutive sample of every mother who gave birth to a baby identified to be of Pacific ethnicity, were approached to participate in the study, which commenced on 15 March 2000, with the final babies being born on 17 December 2000. Middlemore Hospital was chosen as the recruitment site given it had the highest number of Pacific Island births in New Zealand. The Counties Manakau District Health Board, of which Middlemore Hospital is the largest hospital in the region, serves a predominately urban population and is within the boundaries of the Auckland Regional Authority (Paterson et al., 2006).

The 1996 census found 65% of NZ residents identifying as a ‘Pacific Islander’ in New Zealand resided in the area contained within the Auckland Regional Authority (Statistics New Zealand, 1998). Manakau City, within this authority, had the highest proportion (24%) of Pacific Islanders living within its geographical boundaries. This contrasts to the overall New Zealand wide territorial authorities Pacific Island population percentage of 5.8% (Statistics New Zealand, 1999a). The 1996 census found 98.1% of the total Pacific Island child population were living in urban areas, in comparison to only 80.2% of European children. The Auckland region was identified as having the largest proportion of resident Pacific Island children in New Zealand (Statistics New Zealand, 1999b).

The largest Pacific Island ethnic specific group populations of Manakau City comprised of 51% Samoan; 21% Cook Island Maori; and 16% of Tongan ethnicity (Jackson, Palmer, Lindsay, & Peace, 2001). Analysis of the enrolled study participants has found that the inception cohort’s proportions of enrolled Pacific Island ethnic sub-groups are approximately representative of overall ethnic sub-group population data

obtained in the 1996 and 2001 Statistics New Zealand's census figures (Paterson et al., 2002).

3.2.2 Sampling procedures, sampling size, recruitment and consent procedures

During recruitment potential participants were identified by staff from the hospital birthing suite and the Pacific Islands cultural resource unit. The Pacific Development Manager or the Pacific Liaison Officer (under supervision of clinical staff and Auckland University of Technology (AUT University) researchers) initially approached the mothers giving a brief overview of the study and sought permission for future contact, at which time consent was gained for future contact .

To be eligible to be included in the study at least one parent had to be identified as being of Pacific ethnicity and a permanent resident of New Zealand. All babies were born at Middlemore Hospital, or transferred to Middlemore Hospital from one of two satellite birthing units. A cohort sample size of approximately 1,400 mothers of Pacific Island children was sought to allow for potential attrition, with the goal of approximately 1,000 children remaining in the cohort at the 2-year measurement wave. It was envisaged that this would allow sufficient statistical power to detect moderate to large inter-ethnic Pacific Island group comparisons and other key variables (Paterson et al., 2006).

A total of 1,708 potential participants were identified at the hospital birthing units, of which 1,657 were invited to participate in the study. A total of 1,590 (96%) of these consented to a home visit at approximately 6-weeks postpartum for an interview. Potential participants later deemed to be ineligible included those who were later found to not permanently reside in New Zealand, death of baby in preceding period, and those who were untraceable or had left Auckland. This resulted in 1,477 (93%) eligible mothers of which 1,376 (93%) consented to be visited at home at 6-weeks postpartum. Further comprehensive information on the PIF Study inception, methods and cohort characteristics have been previously reported (Paterson et al., 2006; Paterson et al., 2007).

3.2.3 Study protocols and measures

Visits were undertaken at approximately 6-weeks postpartum and eligibility was reconfirmed and informed consent obtained (Paterson et al., 2006; Paterson et al., 2007). The majority of mothers were able to be matched to a female interviewer of their identified ethnicity, who was fluent in both English and the appropriate Pacific Island

language. Once the consent was formally obtained, the 6-weeks one hour interview questionnaire was undertaken in the mother's preferred language.

The questionnaires elicited information on the health and development of the child and explored issues pertaining to the family unit and wider social environment. A variety of survey questions and standardized instruments have been used in the interviews, with every effort undertaken to ensure they were appropriate, acceptable and valid within the Pacific Island population. Although it was acknowledged that this might not always be the case and that all forms of measurement would be reviewed and monitored for their accuracy and reliability, but mindful of the importance of not overburdening the participants in such endeavours (Paterson et al., 2002; Paterson et al., 2006).

Supplementary information was also gained from Middlemore Hospital records and Plunket (provider of community based healthy child development and family support service) only after written consent from the mothers. All data obtained was coded and entered into an electronic database (SPSS Data entry Builder 2.0), with in-depth checking processes undertaken, including a random sample being double entered to estimate any error rate and identify potential issues that will need to be reviewed. Each PIF Study participant has their own unique code or identification (ID) code, and any information linking this code to the participant is stored separately in a password protected file. Access to this information is restricted and is at the discretion of the PIF Study Co-Directors, in accordance to the requirements set out in the Health Information Privacy Code (1994) and the New Zealand Privacy Act (1993). Ethical approval for the study was gained from the National Ethics Committee, the Royal New Zealand Plunket Society and the South Auckland Clinical Board (Paterson et al., 2006; Paterson et al., 2007).

In the following measurement waves contact was made around the birth dates of the child reaching their first, second, fourth and sixth birthdays, and on approval of the primary caregiver of the child, families were revisited by a female interviewer. Informed consent was again obtained by the primary caregiver to participate in the measurement wave and completion of the corresponding measurement wave interview questionnaire was then undertaken. Over the period of the study participants that were unable to be contacted at any measurement waves were later included in subsequent measurement waves if located at a future date. The following time periods define the

period of interest that each measurement wave reviewed; the 6-week measurement wave covered from the day after their birth date to the date of the 6-week interview; the 1-year measurement wave covered from the day after the 6-week interview to the date of the 12-month interview; the 2-year measurement wave covered from the day after the 12-month interview to the date of the 24-month interview; the 4-year measurement wave covered the 12-months before the 4-year interview; and finally the 6-year interview covered the 12-months preceding the date of the 6-year interview (Paterson et al., 2006; Paterson et al., 2007).

The majority of primary caregivers were found to be maternal mothers, however circumstances changed for some mothers over the course of the study, with other people becoming the primary caregiver of the children (i.e. new partner, father, grandparents, and aunts). However biological mothers remained the overwhelming majority of primary caregivers. Currently the study is undertaking interviews for the 'Towards Adolescence' 9-year measurement wave. For ease of exposition, we shall refer to the primary caregiver collectively as "mothers" hereafter in the following sub study, as only seven primary caregivers, of the children who were found to have had an injury listed in the NHI database or reported in the PIF Study questionnaire, were found to not be biological mothers.

3.2.4 Cultural considerations

Careful consideration is given to ensuring cultural considerations are central to both the planning, implementation and the ethos of the study, with integral involvement by Pacific researchers and representatives of the Pacific community in the planning and governance of the study. The Pacific People's Advisory Board (PPAB) composing of Pacific Island community representatives was established to guide the directors and the management team, in the scientific and cultural directions of the PIF Study. They provide support, guidance, knowledge and advise on cultural and practical issues pertaining to the research and participants. Their mandate is to act as an independent review panel for the PIF Study and to "protect and enhance the study to maximise benefits for the Pacific community" (Paterson et al., 2006, p.13).

Due to the frequent use of Pacific Island languages within the New Zealand Pacific community, the initial 6-weeks interview questionnaires were translated into Samoan, Tongan and Cook Island Maori, in an effort to enhance communication given that many of the participants were not born in New Zealand and to recognize and

respect the importance and day to day relevance of their cultural heritage in their lives in New Zealand. Of the 1,376 mothers participating at the 6-week interview only 173 (13%) requested to use a translated questionnaire, the majority of which were of Tongan ethnicity. As such the following measurement wave questionnaires were only available in English, although discussions and clarifications of the English questionnaires may have occurred in a Pacific language during the following interviews, between the participants and the PIF Study interviewers (Paterson et al., 2006; Paterson et al., 2002).

3.3 Study Design

The following sub-study, of the PIF Study, a validity and reliability study, uses quantitative methodology, to assess maternal recall of childhood injuries. These events will be matched to medical attendance events listed in the National Health Index database, which covers public hospital attendances in New Zealand. The National Health Index (NHI) number is a unique, person specific code that is used to track individuals health and disability support usage in New Zealand (NZHIS, 2010). The study uses the National Health Index (NHI) database to glean information from both the NMDS database, which houses hospital inpatient discharge information and some outpatient events, and the NNPAC database, which houses hospital outpatient attendance, on the PIF Study childrens medical attendances at hospital.

The information contained within these databases is used for administrative, research, policy development, health care administration, and management of health and disability support services (NZHIS, 2010). The National Minimum Dataset (Hospital Events) holds mainly clinically coded details on public hospital discharges for inpatient hospital attendance, some limited outpatient attendances, and ED attendances (further information to follow). Whereas the National Non-Admitted Patient Collection holds information on OPCs and ED attendances, which contains no clinical or diagnosis information, under the auspices of the DHB services (Ministry of Health 2008b, 2009d).

The Statistical Classification of Diseases and Related Health Problems Code 10th Revision (ICD- 10-AM-I) ICD codes was used to ascertain injury and non-injury events (National Centre for the Classification in Health, 2000). Children's NMDS and NNPAC information will then be partitioned over the maternal recall periods for each PIF Study measurement wave and compared to the PIF Study childhood injury medical attendance information contained in the PIF Study questionnaires. While in the NHI database, injuries were identified from the primary diagnosis code given for injury

events in the Statistical Classification of Diseases and Related Health Problems Code 10th Revision (ICD-10-AM-I) codes. The use of the ICD-10-AM-I codes is commonly employed in reliability and validity studies to classify the reason for medical attendance events, over a wide range of events including childhood injury events (Davie, Langley, Samaranayaka, & Wetherspoon, 2008). An injury was defined if the ICD-10-AM-I primary diagnostic code was included in the injury chapter between S00 and T98.3. External causes were not used to select injury event status. Sequelae to an injury event were included as mothers were asked to recall medical attendances and no differentiation was sought for return visits for the same condition.

Investigations undertaken aimed to initially establish the validity of the use of maternal proxy report of childhood injuries in the PIF Study, in comparison to the NHI database listing of medical attendance injury events. The original secondary aim was to identify any levels of differential recall within a variety of socio demographic variables, in order to assess whether these variables influenced the degree of concordance between the two measurement sources of injury medical attendance.

3.4 Sample

The study overall sample population included all 1,376 mothers who gave birth to 1,398 children at Middlemore Hospital between the 15 March 2000 and 17 December 2000, who were enrolled in the PIF Study. The eligibility criteria to be included in the study was that mothers had given consent for their child's medical records to be reviewed at Middlemore Hospital, at which time the NHI number was also retrieved. The exclusion criteria included those PIF Study mothers who; did not give approval to have their child's medical records reviewed at Middlemore Hospital; where anomalies existed between the NHI number and PIF Study child demographic details (more in-depth information on the NHI matching process will be discussed in the following NHI data extraction section); and finally those with incomplete data on which to categorize the inpatient/outpatient status of medical attendance events, although this only resulted in one participant being removed from the study in the 4-year measurement wave.

3.5 Data Collection Procedures and Protocols

The following section outlines the process of matching the NHI number demographic information held by the NZHIS to the NHI number held by the PIF Study team. The section outlines the information requested from the NZHIS for matching of injury medical attendance events, the process of transfer of information between the

NZHIS to the PIF Study team, and the translation of the data received from NZHIS into the de-identified data that was used by the researcher and for subsequent data management undertaken. A description will then be given of the measurements used for injury, how these were combined and operationalized into the matching injury variable, and the subsequent categories defined for concordance or not between the two measurement sources.

3.5.1 National Health Index data extraction and creation of de-identified data set for analysis

Initial liaison regarding the study took place between the researcher and the NHI Information Analyst, both via email and telephone correspondence, and a visit to the NZHIS centre. Information on the studies aims were discussed and the Information Analyst advised how the respective databases information could assist in the matching process and recommended the types of information that would be beneficial to extract, to facilitate this process. A copy of the ethics consent for the study was also provided to the NZHIS.

In order for the data to be extracted from the NHI database, the PIF Study Data Manager and Biostatistician, liased with the NHI Information Analyst in order to check the authenticity of the NHI numbers held by the PIF Study team, to ensure they matched with those held within the NHI database. Of the 1398 children at the 6-week interview 17 did not provide consent for medical records to be accessed resulting in 1381 NHI numbers forwarded for review. A file containing the PIF Study participants NHI numbers was sent to the NHI information analyst, at the New Zealand Health Information Service, who identified six incorrect NHI numbers so these participants were excluded from the study.

The remaining NHI number demographic details were sent on a password protected compact disc by registered courier to the PIF Study Data Manager and Biostatistician, for matching. The PIF Study Data Manager and Biostatistician had to personally communicate with the Information Analyst at NZHIS to recieve the password. A rigorous matching procedure of rules was established by the PIF Study Data Manager , including manually checking and reviewing original PIF Study records where indicated, for those with unclear name identification to gain further details to strengthen the matching. See Table 3.1 below for the matching rule and corresponding count of PIF Study participants in each matching category (Taylor, S., personal

communication, October 19, 2009). For those in the manually matched section names were accepted with close matches ie for minor misspellings; or for close but not exact birthdates but where other details corresponded. For example in matching the different NHI numbers, namely the PIF and the NZHIS number, Rule 1 accepted the match as accurate on the proviso that the: birth NHI number provided, the child's gender, the child's date of birth, the child's surname, child's first name, and the child's middle name all matched with the PIF Study NHI number held along with the corresponding details.

Table 3.1: NHI code matching rule protocol

Matching Rule	Count
Rule 1: Birth NHI, Gender, Date of Birth (DOB), Surname, First Name, Middle Name	168
Rule 2: Birth NHI, Gender, DOB, Surname, First Name	689
Rule 3: Birth NHI, Gender, DOB, Surname, Preferred Name	8
Rule 4: Birth NHI, Gender, DOB, Surname (excl. twins)	174
Rule 5: Birth NHI, Gender, DOB, First name (excl. twins)	175
Rule 6: Birth NHI, Gender, DOB, First name (twins)	5
Rule 7: Birth NHI, Gender, DOB, Middle Name	10
Rule 8: Gender, DOB, Surname, Initial	8
Rule A1: Manually matched	117
Rule A2: Manually rejected	20

The researcher was kept independent of this process and at no time had any access to personal information, including completed questionnaires or the actual PIF Study participants NHI numbers (only the PIF Study ID codes), in order to ensure confidentiality was maintained for the PIF Study participants. Following this process the confirmed matched 1,354 NHI numbers, were then sent back to the New Zealand Health Information Service for attachment to the formal request for data which had already been placed (NZHIS), one NHI number was rejected early on due to an incorrect birth date, outside of the time period of interest.

The customised data application requested medical attendance data (from the birthdate of the first child until the last 6-year interview date). Details included the

following information from the NMDS database; NHI number; date of admission; date of discharge; age at admission; age at discharge; length of stay; admission type; medical attendance with an injury flag if primary diagnosis ICD-10-AM-I primary diagnosis code included in the injury chapter between S00 and T98.3; a 'specified injury event flag'; and medical attendance without an injury flag. Data requested from the NNPAC included: NHI number; date of service, age at service, purchase unit code, accident flag, medical attendance without an injury flag, and service type.

The NZHIS Information Analyst used the provided ICD classification codes to dichotomise the medical attendance into the binary outcome - injury or non injury event, no specific details were requested on the specific diagnosis, severity or cause of either the injury or non injury medical attendance event. Further information on the included ICD-10-AM-I codes that were used to dichotomise the non injury and injury status will follow. The inclusion of admission type in the NMDS database allowed identification of acute visits and subsequent follow up visits; and the inclusion of service type and purchase unit code in the NNPAC database facilitated identification of the type of event and matching to place of event which the majority of the PIF Study questionnaires identified. This information was included on the recommendation of the NHI Information Analyst as it enhanced the ability to match NHI listed events with the PIF Study questionnaire data, particularly when events followed straight on from one another. For clarification on the NHI terminology definitions please refer to Appendix 6.

The NNPAC database commenced on 1 July 2006, so the only outpatient data available was restricted to the period from 1 July 2006 till the date of the last child interview in the 6-year measurement. The exception to this was partial capture of outpatient events in the NMDS database. These events are restricted to hospital events where the actual 'treatment time' has exceeded three hours, so even though the children may not get admitted as an inpatient to a ward as such, they are included in the statistics as an inpatient event. Evidence of this practice within the data obtained from the NMDS database revealed instances where children were admitted as inpatients and discharged within the same day, with zero nights spent in hospital.

This practice commenced during the early to mid 1990s in regional emergency departments around New Zealand. Historically there has been acknowledged discrepancies between DHBs on the manner in which they adhered to the definition,

and subsequently if the events included in the NMDS database figures were solely for 'three hour treatment time' or 'included three hours of waiting time' within this definition (NZCYES, 2008; MOH, 2008a). In the Auckland region the three DHBs started reporting these events as 'three hours treatment time' as follows; Waitemata Health – late 1999, Auckland DHB – mid 2000, and Counties Manukau late 2000. Although these dates are approximate as some background activity on the inclusion of this practice was already occurring in the DHB's. By mid 2007 approximately 11 of the 21 New Zealand DHB's were including the '3-hour treatment time' in the NMDS database (Lewis, C., personal communication, June 11, 2010).

Following retrieval from the NMDS and NNPAAC databases the NZHIS Information Analyst sent a password protected CD containing the requested information. The information contained in the CD was provided in Excel format and a delimited text file. The raw data provided by the NZHIS was downloaded and converted by the PIF Study Data Manager and Biostatistician into two separate datasets with consistent variable names and definitions, containing the NMDS and NNPAAC data. The NHI number was replaced with the PIF Study ID code and included the particular measurement wave the medical attendance event was within. This was established by use of the PIF Study child interview dates to review if the medical attendance event date fell within the assessment period prior to the child's corresponding interview. These data sets along with a separate data-set containing the PIF Study demographic information and measurement information was provided to the researcher.

3.5.2 Data management

The researcher then exported the data forwarded by the PIF Biostatistician, from the provided excel format into Stata version 11 (StataCorp LP, College Station, TX, USA, 2009) for analysis. Separate datasets were maintained for the PIF Study data, NHI medical attendance data, and separate datasets were compiled containing the medical attendance events in each PIF Study measurement wave, with consistent variable names used over all the measurement waves. Data was checked for transcription errors, following data transfer into Stata. A chart audit was undertaken to ensure the data transferred into Stata, was consistent with data stored in Excel by double checking a percentage of data cells matched with the PIF Study codes between the PIF Study database and the original data in excel format. This process was repeated for descriptive analyses undertaken where separate data sets were compiled i.e. for range plots illustrating time differences between the 'length of stay' in hospital as compared to

‘number of nights’ in hospital recalled in the PIF Study questionnaires. The data was stored on a password protected computer with appropriate security features installed.

3.5.3 Measurement of injury status in the NHI database and the PIF Study questionnaires

The definition of injury varied over the two avenues of measurement under review, namely the NHI database and the PIF Study questionnaires. In the PIF Study questionnaires no specific definition of injury was given but prompts in the forms of examples of types of injury and accidents were presented. The prompts varied over the course of the study, between different measurement waves and also were different in subsections of the questionnaires pertinent to illness and injuries, and subsequent medical attendance for these events. The majority of the questions ascertained from maternal reports in both the illness/injury identification and the medical attendance sections were dichotomous in nature, with yes/no responses or required a numerical answer i.e. ‘number of nights in hospital’ or ‘number of times’ for injuries. These questions were used, to facilitate further detail on positive responses to identification questions. The injury description questions also varied and as time progressed they became considerably more detailed in their description of what constitutes an injury in order to, aid recall of injury, correspond to the changing nature of childhood injuries at different developmental levels, and to elicit more comprehensive information on the characteristics of the injuries themselves. Refer to Appendix 4, for the injury and illness questions used in each measurement wave.

Participants were also asked to identify treatment associated with each independent injury and illness in the questionnaires, following the earlier identification of any injury or illness that had occurred, as previously discussed. The questions broadly explored a variety of potential avenues for both lay and medical guidance and treatment for injuries and illnesses, these included: solely home treatment by self or within the family (this question ceased at the 4-year measurement wave), traditional healer visits, GP visits, EC visits, ED visits, specialist visits (SPC), and finally OPC visits over some or all of the measurement waves. The questions used were not standardized child injury questions. See Appendix 5 for further details on medical attendance event questions.

Measurement tools that were to be employed in the secondary analysis include the use of standardized assessments for the following variables; Maternal mental

health - General Health Questionnaire GHQ and GHQ12 (Goldberg & Williams, 1988) and Edinburgh Postnatal Depression Scale (Cox & Holden, 2003); The Alcohol Use Disorders Identification Test (AUDIT) (Babor, Higgins-Biddle, Saunders, & Monteiro, 2001); Child discipline Parent Behaviour checklist (PBC) – (Fox, 1994) and Parenting Practices questionnaire (Robinson, Mandelco, Frost Olsen, & Hart, 1995); and for Intimate Partner Violence – Conflict Tactics Scale (Straus, 1979). Other variables measured by self report, with the use of non standardized questions, were also used in the PIF Study questionnaires. Of which the following will also be utilized in the secondary analysis: household income, English language verbal and comprehension skills, employment status of parents, place of birth, ethnicity, marital status, parity, and maternal educational qualifications.

While the definition in the NHI, as previously stated, was defined as an injury if the ICD code was included in the injury chapter between S00 and T98.3. In an effort to capture the potential impact of the differences between what mothers perceive an injury to be and how the ICD codes define an injury (from a medical diagnostic perspective), a ‘specified injury event flag’ with redefined ICD injury codes for the dichotomising of injury versus non injury was requested. To review the full list of excluded categories in the ‘specified injury event flag’ events see Appendix 3. The items that were excluded from the injury chapter included injuries caused by medical procedures namely ‘Complications of surgical and medical care, not elsewhere classified’ T80-T98.3. This is commonly advocated in injury research methodological recommendations (Cryer, Langley, & Stephenson, 2004).

Other injury categories excluded were: blisters, insect bites, heatstroke and sunstroke, other effects of reduced temperature, effects of other deprivation, effects of other external causes, effects of air pressure and water pressure, toxic effect of noxious substances eaten as seafood, toxic effects of noxious substances eaten as food, and lastly toxic effect of contact with venomous animals. While these categories fit within the definition of injury in a strict sense, the question of whether parents would include these events to our knowledge appears to be unquantified. The researcher reviewed the literature for previous studies that examined the difference between parent’s perceptions of what constituted an injury in comparison to medical understanding of injuries, as defined by the primary diagnosis and the IC-10-AM-I. In the absence of locating any information, the above consensus of codes to exclude was reached by discussion among PIF Study research staff (both Pacific and non Pacific; parents and non parents), as to

the areas where parents perceptions may differ to clinical definitions as used in the ICD-10-AM-I, hence the identified codes where discrepancies could exist were excluded as indicated in the ‘specified injury flag’ provided along with the overall data.

During the course of the study the New Zealand Health Information Service used ICD-10-AM 1st edition until July 2001; ICD-10-AM 2nd edition from July 2001 to July 2004; and lastly the ICD-10-AM 3rd edition commencing in July 2004. All dichotomised data extracted from the NHI database is mapped forward to each current respective version as it is introduced, in order to maintain consistency in reported data (Lewis, C., personal communication, June 29, 2009).

3.5.4 Matching injury variable and categories created from the combined data

Prior to the injury matching variable and associated matching categories being defined, consideration was given to characteristics in the dataset that could impact on the matching process. Separate events that commenced on the same date may have been inter hospital or internal hospital transfers. Although they may have been identified as separate events for hospital administrative purposes, it was considered unlikely that the majority of mothers would have reported these as separate events. Subsequently these events were amalgamated into one event. There was one exception where a PIF Study mother recalled both events separately, subsequently on this occasion only they were treated as separate events as presented in the NHI data, and are not included in the figures for same event admissions. It is plausible that this mother may have had greater knowledge of the administrative system or possibly have been an inter hospital transfer which may have influenced them recalling each event separately.

Manual matching was employed to review the injury and non injury events from both the NHI injury listings and PIF Study questionnaires. A template was established for each separate measurement wave with lists of reported PIF Study inpatient reported events, PIF Study outpatient reported events, NHI listed inpatient events, and NHI listed outpatient events. The PIF Study questionnaire reported inpatient and outpatient injury event templates contained; the PIF Study codes; if the injury event was also recorded in the NHI listings as an injury event; the number of nights spent in hospital recorded in the PIF Study questionnaire; the length of stay recorded in the NHI corresponding listing; the presence of other non injury admissions including the age, reason, place of attendance; the number of nights spent in hospital stated in the PIF Study

questionnaires; any other non injury admissions listed in the NHI database including the length of stay; admission type; and the place of medical attendance.

Whereas the templates for the NHI reported inpatient and outpatient injury events contained; the PIF Study codes; if the injury event was recorded in the PIF Study listings as an injury event; the length of stay in hospital recorded in the NHI listing; the number of nights in hospital recorded in the corresponding PIF Study questionnaire; the presence of other non injury admissions including the age, reason, number of nights spent in hospital and place of attendance stated in the PIF Study questionnaires; any other non injury admissions listed in the NHI database including the admission type; and the length of stay. The degree to which these were completed was reliant on to what extent the events matched, or other non injury events were recorded in either measurement source.

In order to review NHI listed injury data and PIF Study questionnaire reported injury data for potential matching five categories were formed that encompassed all options for matching or none matching. These include ‘complete match’, ‘time difference’, ‘reason difference’, ‘time and reason difference’, and finally the ‘no report’ category. These categories were used for both the listed and reported inpatient and outpatient injury events in the NHI database and the PIF Study questionnaires, but their meanings varied slightly, as described in the following definitions.

The ‘complete match’ category is defined as any stated injury event that is recorded in both the NHI list and PIF Study questionnaire for inpatient or outpatient injury events. All details correspond i.e. length of stay in either inpatient or outpatient events, in both sources. Whereas the ‘time difference’ category is used to capture those events that appear to match i.e. both reported as injury events, but there is a time difference between the reported ‘number of nights spent in hospital’ by PIF Study participants and the ‘length of stay’ in listed in the NHI database. This could be any combination of events between the PIF Study reports and the NHI listing i.e. between either a PIF Study outpatient injury event or an NHI listed outpatient event or could be a NHI listing as an inpatient, with a corresponding PIF Study outpatient event recorded.

The ‘reason difference’ category focused on those events where an injury was reported in either the NHI database or PIF Study questionnaires and an injury event was not recorded in the other measurement source, but a non injury event was found that had the potential to match up to the injury event initially identified. While the ‘time

and reason difference' category captured events where for example an NHI injury event had no corresponding PIF Study injury questionnaire event, but a non injury event appeared to match, but with different reporting of the length of time of the event between the PIF Study questionnaire and the NHI listing; or conversely where an NHI injury listed event had no corresponding injury event reported in the PIF Study questionnaires but a non injury event could potentially match, with a time difference between the PIF Study reported 'nights in hospital' and the NHI listed 'nights in hospital'.

In both the 'reason' and 'time and reason' categories the injury events were initially reviewed by cross matching the age of child at the non injury medical attendance event that corresponded in the alternate measurement method, to ensure the events were in fact a potential match. The only exception was for the 6-year events which were unable to be cross checked in this manner due to the pertinent question – 'age at which medical event occurred', not being asked in the 6-year questionnaire, as it had been in all prior questionnaires over the course of the study. The criteria used was 'match' defined as the age of the child stated in the PIF Study questionnaire, for a non injury event corresponds to the NHI injury event date . A 'close match' was defined as the child's age at the time of the event (as stated in the PIF Study questionnaire) being within one month of the non injury PIF Study questionnaire event, for the NHI injury event. The same definition was also used for a PIF Study injury event which potentially corresponds to a NHI non injury event. Any that did not fit within these defined 'close match' or 'match' age criteria were moved into the 'no report' category.

The final category 'no report' essentially captures all events where no injury event is recorded in the PIF Study questionnaire or NHI listing, but conversely has been reported in the other. Also if a non injury event appears originally to fit within the definition of 'reason difference' or 'time and reason difference' but on further investigation of the date of the event in relation to the age of the child was found not to correspond, it was relegated to the no report category. PIF Study participants with multiple admissions, over and above the allocated space in the questionnaires i.e. due to the restricted number of answers available, were also included in this section, due to the inability to differentiate between a multitude of medical attendances, both injury and non injury events. Also included in this category were events that were very close together in time, resulting in it being indiscernible to state which category they realistically would come under.

For the purpose of consistency henceforth potential matching categories will be defined as including the 'complete match' and 'time difference' categories. The inclusion of the 'time difference' category in the overall matching categories in frequency discussions in the results chapter is in recognition of the fact that time differences are potentially impacted on by administrative components of hospital definitions, mothers memory of events and mothers perceptions of what constitutes 'a night in hospital'. Both the PIF Study participants and the NHI database had also agreed on the fact that there had been an actual injury event that resulted in a medical attendance inpatient or outpatient event. With the no match categories deemed to include the 'reason difference', 'time and reason difference', and 'no report' categories.

3.6 Statistical analysis and presentation of results

All statistical analyses were performed using Stata 11 IC (StataCorp LP, 2009b). Frequency distributions were undertaken in both Microsoft Excel 1997-2003 and Stata 11 IC. A significance level of $\alpha=0.05$ was set to determine the statistical significance in all analyses undertaken. Each measurement wave is considered separately and no formal across wave analysis was undertaken. Descriptive analysis was used to characterise the reported injuries and injury matching category characteristics, during each measurement wave. All descriptive data is presented in frequencies and percentage totals, with ranges and means included where appropriate

To commence the analysis descriptive statistics were undertaken to characterise the injury events. These focus on the PIF Study reported injury events and NHI listed injury events, including the frequencies of inpatient versus outpatient status. Fisher's exact test of significance was undertaken to determine the level of statistical significance between the frequencies of injuries in the two measurement methods. It was chosen due to its suitability of use with categorical data and its capacity to test association in two-by-two contingency tables. It is also recognised to be responsiveness to small sample sizes and is unaffected by unequal distribution of frequencies within the contingency table cells.

The following areas were then reviewed in an attempt to reveal factors that may have contributed to any differences found in the concordance between the PIF Study reports of childhood injuries and the NHI database listings of childhood injuries; identification of injury occurrences in the PIF Study questionnaires prior to medical attendance questions; place of injury visit identified in the PIF Study questionnaires; and the location of medical attendance events identified in PIF Study questionnaires,

partitioned over matching categories in measurement waves 1-year, 2-years and 4-years; and the impact of redefined ICD injury code events impact on 'injury versus non injury status' for medical attendance events. Frequency distributions were presented and where indicated Fisher's exact test and χ^2 goodness-of-fit test was undertaken to determine the level of statistical significance of the reported frequencies.

The following categories within the matching criteria were then reviewed including: the characteristics of matching category injury events over the NHI database and PIF Study questionnaire inpatient and outpatient events, the 'time difference' matching category and the 'time' component of the 'time and reason' matching category, and finally the 'reason difference', and 'time and reason difference' matching categories. Once again frequency distributions were presented, with the use of Fisher's exact test to determine the level of significance. A range plot was used to illustrate the difference between the PIF Study mothers recall of 'number of nights spent in hospital' compared to the 'length of stay' reported in the PIF Study questionnaires, in the 'time difference' category. Ranges were reported, along with the median value over the included injury events. The Wilcoxon signed rank non-parametric significance test was used to determine the significance of the difference between the 'number of nights spent in hospital' as defined by the PIF Study mothers and the 'length of stay' as listed in the NHI database injury listings. This test was chosen due to the time periods being matched and ordinal in nature, and seeks "to test the equality of matched pairs of observations, with the null hypothesis that both distributions are the same" (StataCorp LP, 2009, p.1719).

Following the above descriptive statistics, the injury matching variable matching categories, namely 'match total', 'time difference', 'reason difference', 'time and reason difference', and 'no report' were each allocated a numerical value, in preparation for assessment of the degree of concordance between the PIF Study maternal reports of injury and the NHI listing of injuries. First McNemar's test of symmetry was undertaken to identify any existing direction of misclassification between the PIF Study mother's reports of injuries and the NHI databases listing of injuries, by reviewing the symmetry of the discordant injury reports between the NHI database listings and PIF Study mother's reports. McNemar's test of symmetry is used when measurements are undertaken in matched samples to illuminate any systemic bias (represented by systematic disagreement) between the two measurement methods,

namely the injury listings in the NHI database and the injuries reported in the PIF Study questionnaires.

The kappa statistic was then used to reveal the agreement beyond chance between PIF Study participants reporting of childhood injuries in the questionnaires and the listing of injuries in the NHI database. The use of an unweighted kappa statistic is recommended in this situation where categorical data is nominal and non ordinal in nature (White & van den Broek, 2004). The levels of agreement between the PIF Study mothers report and the NHI database listings were then classified using Landis and Koch's characterisation. The secondary analysis was intended to be undertaken using regression analysis (Rothman et al., 2008).

3.7 Ethics

Ethical research approval for the study was sought and gained from the Northern X Regional Ethics Committee, under expedited review of observational studies, and the Auckland University of Technology Ethics Committee (AUTEC). Approval was given to proceed with this sub-study without gaining individual consent from the participants, with the rationale outlined in the following section. Individual consent for the use of de-identified data was not sort on scientific, practical, and ethical grounds. Refer to Appendices 1 and 2, for ethical consent forms.

3.7.1 Rationale for approach undertaken

In the inception stages of the study, prior to applying for ethical consent, the intention had been to obtain individual consent from the PIF Study participants to review their NHI information. This was necessary in order to facilitate the matching process between the NHI database information of medical attendances for childhood injury and the PIF Study mother's recall of childhood injury as reported in the PIF Study questionnaires. After meeting and consultation with the senior management team of the PIF Study, the approach to be undertaken changed focus and approval for the use of the NHI database without specific consent for this sub-study in accordance with the Health Information Privacy Code (Office of the Privacy Commissioner, 2008) was sought. Only those participants who agreed to have their child's hospital records reviewed at the 6-week measurement wave were included, those who refused were not accessed.

The researcher acted upon recommendations from the Senior Pacific Research Fellow, Chairperson of the PPAB and Co-ordinator of the PIF Study and PPAB

members to undertake the research without gaining individual consent. The primary rationale for this recommendation was to reduce the burden to participants for a study that is deemed to be of minimal risk. A recognized strength of the study to date has been the successful recruitment and retention of what has been considered a 'hard to reach population', which is acknowledged to be vital to the long term success of the study. Crucial to the success of the PIF Study is awareness of the impact of the study on participants as retention of participants in the long term results in more robust data. Subsequently any extra request that could lead to anxiety or stress on participants needs to be considered accordingly.

An overwhelming or unfair burden on individuals is acknowledged as an important consideration within longitudinal studies and subsequent sub studies (Beauchamp et al., 1991; Bouton & Parker, 2007; Martin & Marker, 2007). Boulton and Parker (2007) are of the view that the incremental relationship that is built during a longitudinal study and the development of trust may be impeded by the inclusion of consent for all procedures. This may be counterproductive to the establishing relationship and equally so can impact on established relationships as well. The use of data from alternate available sources has already been deemed to have decreased participant burden, which is felt to have contributed to the success to date (Paterson et al., 2007). A careful balancing act is therefore crucial in not overburdening participants and impacting on their trust and motivation to continue; and not risking losing trust due to not respecting their privacy; both of which are ultimately not desirable.

While seeking consent is of prime importance in ethics, it is irresponsible to not consider the environment in which such consent is given, and how this can impact and ultimately effect the potential benefits to society which flow on from longitudinal studies. To gain permission to proceed without consent could be said to be disrespectful to autonomy and subsequently therefore do harm. If the converse is true if one does not proceed with the study, harm could be done to the participants due to the possibility that future data collection methods may not elicit accurate data and subsequently inappropriate recommendations could be made, which could ultimately impact on society at large. This is reinforced in the ethical guidelines for observational studies as follows "Projects without scientific merit waste resources and needlessly use participants' donated time" (National Ethics Advisory Committee, 2006, pg. 10).

3.7.2 Considerations and processes for the PIF sub study

This study provides an opportunity to show whether the maternal recall of events reported were accurate or not. It will also highlight if there are differences between participants of different characteristics. By including all participants in the study the findings are more robust. If individuals had a choice to participate in the sub-study they may differ in characteristics to those who give consent, which would further impact on the validity of the study (Miller, 2008; Vandenbrouche et al., 2007; Woolf, Rothemich, Johnson, & Marshland, 2000). To not undertake a validity/reliability study could be considered unethical and irresponsible given the knowledge and previous findings that point to the potential of information bias existing and given the conflicting evidence of the use of maternal recall in child health and medical attendance studies (Harel et al., 1994; Rice et al., 2007; Ungar et al., 2007).

The PIF Study children were born from March to December 2000 so the current 9-year measurement wave consent and assessments are presently being undertaken. If consent for this sub-study was to be obtained it would be necessary to seek permission at the home visits and return to those already visited. Practical factors such as time limitations on this study due to academic requirements, also the desire not to overburden participants with an extra consent at the time of main data collection, all contributed in the decision to proceed without gaining individual consent from the PIF Study participants.

Mothers had self-reported considerably more detail in the PIF Study questionnaires, giving specific information on; injury types, frequencies, if treatment was sought and by whom, hospital attendance, and time spent as an inpatient admission. It was believed that this level of information might potentially carry more risk (with small numbers and potentially identifiable participants), which resulted on information sought focusing on injury/non injury events only, rather than the provision of detailed injury information. It was believed that the proposed study is relatively low risk, when considered alongside the information already obtained in the PIF Study on highly sensitive data, such as intimate partner violence and illicit drug use.

By the very nature of the study in seeking to clarify if maternal self-reporting captures child injuries in an accurate manner, the use of potentially identifiable information has to be used. To ensure anonymity the Data Manager and Biostatistician in the PIF Study team independently from the researcher and supervisors; reviewed the study participants NHI numbers and undertook the tasks of ensuring the NHI numbers

held on the PIF Study participants, matched with the NZHIS demographic information held for the PIF NHI numbers; linked the NHI provided information on medical attendances for each of the NHI numbers to the PIF Study participant codes; and subsequently provided the researcher with all the 'de-identified data' using only the PIF Study codes.

Public health ultimately seeks to improve population health for the health of all communities and individuals in society. In order to do this as efficiently as possible individuals information is used to build a clearer picture of risk factors and attributes that may impact on the health of populations, that subsequently may lead to health inequalities or in fact compound pre existing inequalities. While respecting the right of individuals for privacy the researcher has no direct interest in the individual data per se, only the resulting aggregate data (Couglin, 2006; Gostin, 2001; Miller, 2008). The privacy risks were reduced by the careful consideration and application of creating the de-identified dataset, data management, analysis and reporting as already reported. It was acknowledge that the risks could be difficult to predict, but the researchers believed with careful consideration and procedures, all efforts are to be undertaken endeavouring to protect the participants interests, while promoting public good.

We are mindful of the reflection "The social benefits obtained from research are substantial and reduce or eliminate the risks that likely would not otherwise be reduced or eliminated" (Beauchamp et al., 1991, p.1635). We believe it is crucial to ensure the PIF Study findings are based on the most accurate data and seek to review if we have in fact captured this through the use of maternal recall. This knowledge has implications, not just to add knowledge to the PIF Study, Pacific childrens health in the field of injury prevention, but also in the wider realm of child health considerations.

3.7.3 Unique considerations for children

The Convention on the Rights of Children article 24 states "Parties recognise the right of the child to the enjoyment of the highest attainable standard of health" (United Nations, 1990, p.7). Children are identified as one of the most vulnerable in society and as such are entitled to protection by society and individuals alike. Young children are citizens in their own rights but cannot speak for themselves and act as their own advocates. If research is not undertaken to illuminate their needs this could be said to violate their rights (Kopelman, 2000).

Quortrup (1997) highlights the absence of child specific data availability across diverse fields in the social sciences and attributes this to the position of children in society and their marginalized role in decision making and inability to speak for themselves. The irony of both individuals and society alike extolling children to be ‘the most precious members of society’ and conversely the absence of data to inform policies that facilitate childrens health and wellbeing is apparent. Quortrup describes children as the “Invisible group par excellence in our society” (p. 87). He poses the impact of the sacrosanct nature of the family as a private zone, has contributing to this lack of knowledge. While not denegrating the crucial roles of parents and families in their roles as caregivers for their children, the need to illuminate the very issues that are contained within family life, collectively and on an aggregate level are essential and pivotal in fostering a greater understanding of childrens needs. With the ultimate aim to be to improve both childrens and their families health and wellbeing.

It has been proposed that health data can act as an advocate or protector of childrens health by being independent to children and their families (Rigby, Kohler, Blair, & Metchler, 2003; Rigby, 2005). Gostin (2001) views data to be a powerful medium by which its responsible use can enhance the ability for societal aspirations for good health to be attained and the protection of children simultaneously be enhanced. As identified in the Guidelines to Observational Studies two key areas prevail with those with diminished competence to consent - the inherent vulnerability and the potential injustice by such groups being excluded from benefits resulting from observational studies (National Ethics Advisory Committee, 2006). We believe the responsible use of the data from the NHI database seeks to uphold these principles while ensuring potential harm is minimized, to result in information that is of significant public benefit in enhancing knowledge about the factors that impact on childhood injuires, who as acknowledged are unable to advocate for their needs.

Children have a right to a satisfying, safe childhood; they have a right to claim "first call" on resources, both personal and public; and the most valuable must become our pririoty, for their sake and in the interests of social justice, national sustainability and national self respect. (Hanna & Hasswell, 2006, p. 3)

4: Results

4.1 Introduction

Following ethical approval and successful negotiations between the NZHIS and the researcher to obtain appropriate customized data from both the NMDS and NNPAC databases, the PIF Study Data Manager co-ordinated the following activities to attain the child injury data from the NZHIS, communication with NZHIS information analyst to facilitate the matching of the NHI numbers and receiving of the provided NHI data from the NZHIS. The PIF Study Data Manager then undertook appropriate procedures to ensure all data to be provided to the researcher was in a de-identified PIF Study code format, including data from both the NHI database and the PIFstudy questionnaires. At which time the PIF Study Data Manager and Biostatistician provided the de-identified data set for the researcher to commence analysis. Data was provided for a total 1,354 children (97%) out of the overall total of 1,398 children in the PIF Study cohort at 6-weeks.

Initial review of the matching process to be undertaken revealed limitations in the 6-year PIF Study database that restricted the use of previously used items that had been found to facilitate the matching process with injury events from the NMDS database i.e. the child's age, place of attendance and crucially no prompt was given for outpatient clinics in the 6-year questionnaire. This was important as the NNPAC database captured outpatient attendances, the majority of which were outpatient clinic visits. There was also no way to differentiate between an 'EC' or 'ED' venue.

When reviewing the injury events that occurred in ED for those who had not already been interviewed for the 6-year measurement wave only nine fell within the appropriate time frame. Some were reported in both the NNPAC and the NMDS. This combined with the previous experience of injury events appearing to match with non injury events, potential misinterpretations by inconsistencies within the PIF Study questionnaires, and the inherent complexities of amalgamating the NMDS and NNPAC listings together to match with the PIF Study questionnaire resulted in a decision not to use the NNPAC listings. This resulted in only the NMDS database injury and non injury events being included in all analysis.

4.2 Sample Characteristics

In total, 1,477 mothers were eligible for the PIF Study, 1,376 (93.2%) participated at the baseline 6-weeks interview, 1,224 (82.9%) completed the 1-year interview, 1,144 (77.5%) completed the 2-years interview, 1,048 (71.0%) completed the 4-years interview and 997 (67.5%) completed the 6-years interview (Paterson et al., 2007). Respondent's baseline socio-demographic characteristics of the total PIF cohort (prior to the current sub-study) are presented in Table 4.1. The ethnic frequencies in Table 4.1 were broadly similar to those seen in the general New Zealand Pacific population (Paterson et al., 2006; Paterson et al., 2007).

Table 4.1: Socio-demographic profile of maternal and infant characteristics measured at the 6-weeks measurement wave (N=1,376).

Variable	n	(%)
<i>Age (years)</i>		
<20	111	(8.1)
20-24	354	(25.7)
25-29	366	(26.6)
30-34	324	(23.6)
≥35	220	(16.0)
<i>Ethnicity</i>		
Tongan	650	(47.2)
Samoan	289	(21.0)
Cook Island Maori	232	(16.9)
Other Pacific	106	(7.7)
Non-Pacific	99	(7.2)
<i>Marital status</i>		
Married/de facto	1,107	(80.5)
Single/divorced/widowed	269	(19.5)
<i>Highest educational qualifications</i>		
No formal qualifications	535	(38.9)
Secondary	464	(33.7)
Post-secondary	377	(27.4)
<i>Parity (the number of live-born children delivered)</i>		
1	374	(27.6)
2-4	768	(56.6)
≥5	215	(15.8)
<i>English language fluency</i>		
Proficient	851	(61.8)
Otherwise	525	(38.2)
<i>Years lived in New Zealand</i>		
0-4	215	(15.7)
5-9	162	(11.8)
≥10	996	(72.5)
<i>Current Smoking Status</i>		
Non-smoker	1,029	(75.0)
Smoker	343	(25.0)
<i>Household income</i>		
≤\$20,000	457	(33.2)
\$20,001-\$40,000	710	(51.6)
>\$40,000	161	(11.7)
Unknown	48	(3.5)
<i>Infant Sex</i>		
Female	667	(48.5)
Male	709	(51.5)
<i>Infant multiplicity (live births)</i>		
Singleton	1,354	(98.4)
Twin	22	(1.6)

The sub-study commenced with 1,354 children at 6-weeks. Following attrition in each respective measurement wave, the following number of children in the sample at each measurement wave included; 1,205 at 1-year, 1,137 at 2-years, 1,049 at 4-years, and 996 at the 6-year measurement waves. In the 4-year measurement wave one participant record was excluded from the main injury analyses, as they had not stated if the injury event was outpatient or inpatient in nature. Missing data relating to other questions is explained to in the text where encountered. Where percentages are given in the text they refer to the percentage of the total cohort at the corresponding measurement wave, unless stated otherwise, or apparent. As stated previously, for ease of exposition the primary caregivers shall be referred to as ‘mothers’, due to only seven not being biological mothers of the PIF Study children that were identified over all measurement waves as having had an injury (See Table 4.3, following, for further information).

Baseline data on the characteristics of the 1, 354 children included in the sub study at 6-weeks found, 663 (49%) were females and 691 (51%) were males. Of these 1311 (97%) were singletons and 43 (3%) were twins. In relation to the maternal characteristics overall in their relationship to the child, there were 1346 (99%) birth mothers, 6 (0.4%) adoptive mothers, and 2 (0.2) others (which included one foster mother). The age of the mothers revealed 108 (8%) were <20-years of age, 705 (52.1%) were between 20-29-years of age, 496 (37%) were between 30-39-years of age, and 45 (3.3%) were ≥40-years of age. Of the mothers, 632 (46.7%) were stated to be of Samoan ethnicity, 230 (17%) Cook Island Maori, 59 (4.4%) Niuean, 290 (21.4%) Tongan, 43 (3.2%) Other Pacific, and 100 (7.4%) of non-Pacific ethnicity.

Of these mothers, 901 (66.5%) stated they were born in New Zealand and 453 (33.5%) elsewhere. Of which 99 (7.3%) stated they had lived in New Zealand for 0-2-years, 167 (12.3%) for 3-5-years, 140 (10.3%) for 6-10-years, and 945 (60.8%) had lived in New Zealand for >10-years. Overall 3 (0.2%) mothers did not answer this question. In relation to marital status, 1090 (80.5%) identified themselves to have a partner and 264 (19.5%) to not have a partner. In regards to educational qualifications, 522 (38.6%) had no formal qualifications, 455 (33.6%) secondary school qualifications, and 377 (27.8%) reported having post secondary school qualifications. Finally in relation to household income per annum, 450 (33.2%) annual incomes were between \$0 - \$20,000, 693 (51.2%) incomes were between \$20,000 - \$40,000, and 164 (12.1%) income were >\$40,000, with 47(3.5%) reporting ‘unknown’ annual incomes. Many PIF

Study participants identified themselves to be fluent in more than one language, with 353 (26%) mothers overall reporting that they could speak more than one language. English was the most common language with 843 (49.4%) mothers identifying themselves to be fluent in English, followed by; 493 (29%) fluent in Samoan; 268 (16%) fluent in Tongan; 64 (4%) fluent in Cook Island Maori; 19 (1.1%) fluent in Niuean; and 19 (1.1%) fluent in Other Pacific languages. In relationship to the statement “Do you understand English well” 671 (49.6%) strongly agreed; 535 (39.5%) agreed; 110 (8.1%) neither agreed or disagreed; 22 (1.6%) disagreed; and 16 (1.2%) identified that they strongly disagreed with the statement. In responding to the statement “Do you speak English well” 713 (52.7%) identified the option ‘alot’; 318 (23.5%) ‘quite alot’; 234 (17.3%) ‘somewhat’; 77 (5.7%) ‘a little’; and 12 (1.9%) identified that they did not agree with the statement ‘not at all’.

4.3 Characteristics of injury events

From the overall sample of 1,354 PIF Study children, a total of 184 separate PIF Study participants were found to either have reported in the PIF Study questionnaires or had been listed in the NHI database as either having at least one inpatient or outpatient injury event, over the 6-week, 1-year, 2-years, 4-years, or 6-year measurement waves. Of the 184 PIF Study participants 5 children were reported in the PIF Study questionnaires or listed in the NHI database as having experienced an injury in the 6-week measurement wave; 38 children at 1-year; 80 children at 2-years, 35 children at 4-years, and 45 children at the 6-year measurement waves. Of these 166 (12%) individual PIF Study participants were found to have reported or listed injury events in only one measurement wave with a total of 218 injury events, 18 (1.3%) individual PIF Study participants over two measurement waves with a total of 40 injury events, and 1 (0.07%) PIF Study participant had a total of 5 injury events over three measurement waves.

In the six children reported or listed with three injury events over two measurement waves, on all occasions one wave included two events which both fell into a matching category. The scenario was also the same for the one PIF Study participant with five injury events recorded or listed over three measurement waves. In this instance two sets fell within a matched category in two measurement waves. A further five PIF Study participants reported injury events in more than one measurement wave, but did so in the SPC, EC or OPC venues; so were therefore unable to be captured in the

analysis of the NHI database listings and PIF Study questionnaires and were not included in the above figures.

Figure 4.1 depicts the frequencies of a total of 259 reported injuries in the NHI database and PIF Study questionnaires that comprised of 5 injury events at 6-weeks, 50 at 1-year, 108 at 2-years, 41 at 4-years, and 55 injuries at the 6-year measurement waves.

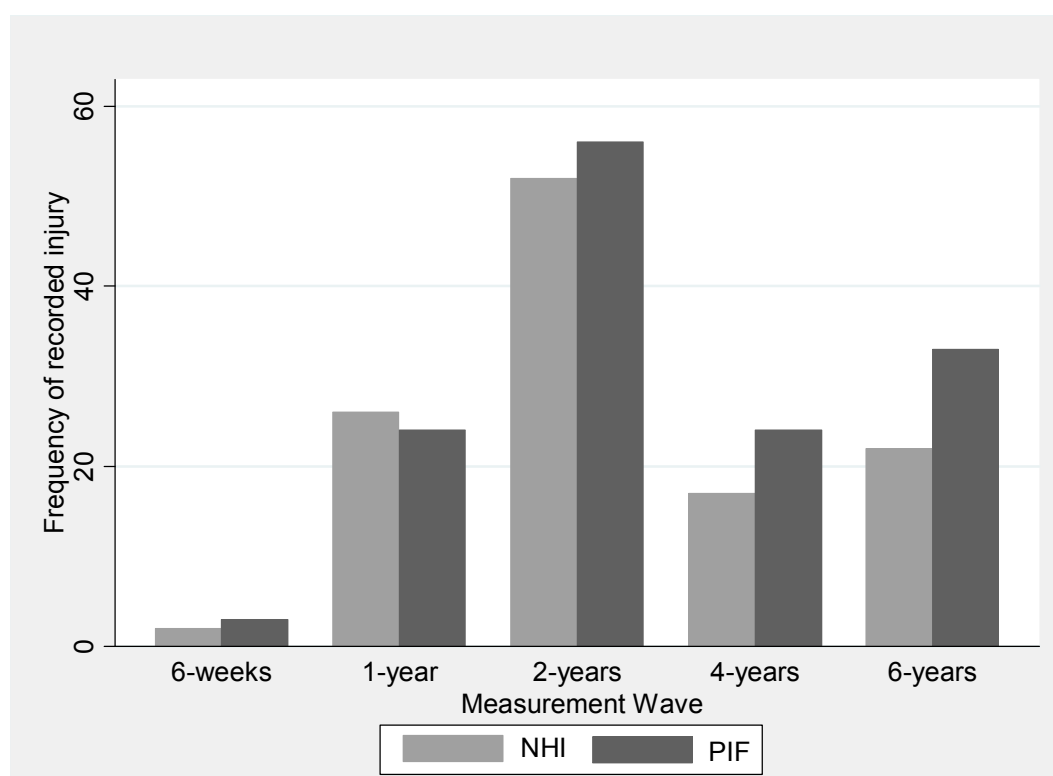


Figure 4.1: *Frequency of recorded injury events by NHI and PIF Study measurement waves*

A total of 120 events were listed in the NHI database and comprised of 3 injury events at 6-weeks, 26 at 1-year, 52 at 2-years, 17 at 4-years and 22 injuries at the 6-year measurement waves. In comparison a total of 139 injury events were reported in the PIF Study questionnaires which comprised of 2 injury events at 6-weeks, 24 at 1-year, 56 at 2-years, 24 at 4-years and 33 injuries at the 6-year measurement waves.

4.3.1 Sub study characteristics

See Table 4.2 for the demographic profile of children from the overall sample that were reported in the PIF Study questionnaires or listed in the NHI database, as having had an injury, over all measurement waves. Whilst Table 4.3 shows the

demographic profile of the primary caregiver/mothers of the children where an injury was reported in the PIF Study questionnaires, or listed in the NHI database.

Table 4.2: Frequencies (percentage) of socio-demographic characteristics and potential confounding variables for child characteristics measured over measurement waves at 6-weeks (n=5), 1-year (n=38), 2-years (n=80), 4-years (n=35) and 6-years (n=45) postpartum.

Infant Characteristics	Measurement Waves									
	6-weeks		1-year		2-years		4-years		6-years	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
<i>Gender</i>										
Female	5	(100)	13	(34)	32	(40)	10	(29)	16	(35)
Male	0	(0)	25	(66)	48	(60)	25	(71)	29	(65)
<i>Multiple Birth Status</i>										
Singleton	5	(100)	38	(100)	77	(96)	34	(97)	45	(100)
Twin	0	(0)	0	(0)	3	(4)	1	(1)	0	(0)

Table 4.3: *Frequencies (percentage) of socio-demographic and potential confounding variables of primary caregiver, measured over measurement waves at 6-weeks (n=5), 1-year (n=38), 2-years (n=80), 4-years (n=35) and 6-years (n=45) postpartum*

	Measurement Waves									
	6-weeks		1-year		2-years		4-years		6-years	
	n	%	n	%	n	%	n	%	n	%
<i>Relationship to Child</i>										
Birth Mother	5	(100)	38	(100)	77	(96)	35	(100)	41	(91)
Adoptive Mother	0	(0)	0	(0)	1	(1)	0	(0)	0	(0)
Other	0	(0)	0	(0)	2	(2)	0	(0)	4	(9)
<i>Age of Primary Caregiver (years)</i>										
<20	1	(20)	2	(5)	3	(4)	0	(0)	0	(0)
20-29	1	(20)	23	(60)	34	(42)	14	(40)	14*	(32)
30-39	3	(60)	10	(26)	34	(42)	16	(46)	23	(52)
≥40	0	(0)	3	(8)	9	(11)	5	(14)	7	(16)
<i>New Zealand Born</i>										
Yes	1	(20)	11	(29)	22	(28)	12	(34)	16	(36)
No	4	(80)	27	(71)	58	(73)	23	(66)	29	(64)
<i>Marital Status</i>										
Partnered	5	(100)	32	(84)	65	(81)	32	(91)	36	(80)
Non partnered	0	(0)	6	(16)	15	(19)	3	(86)	9	(20)
<i>Ethnicity</i>										
Samoan	5	(100)	17	(45)	39	(49)	16	(46)	20	(44)
Cook Island Maori	0	(0)	7	(18)	20	(25)	4	(11)	10	(22)
Niuean	0	(0)	0	(0)	2	(2)	1	(3)	3	(7)
Tongan	0	(0)	9	(24)	12	(15)	10	(29)	8	(18)
Other Pacific	0	(0)	2	(5)	1	(1)	0	(0)	1	(2)
Non Pacific	0	(0)	3	(8)	6	(7)	4	(11)	3	(7)

*Note: Indicates missing *data*

Continued overleaf

	<i>Measurement Waves</i>									
	6-weeks		1-year		2-years		4-years		6-years	
	n	%	n	%	n	%	n	%	n	%
<i>Number of years lived in New Zealand at baseline</i>										
0-2	0	(0)	3	(8)	4*	(5)	1	(3)	2	(4)
3-5	0	(0)	4	(11)	12	(15)	4	(11)	3	(7)
6-10	0	(0)	6	(16)	11	(14)	5	(14)	7	(15)
>10	5	(100)	25	(66)	52	(65)	25	(71)	33	(73)
<i>Highest Educational Qualification</i>										
No formal qualifications	3	(60)	13	(34)	26	(32)	12*	(36)	11	(24)
Secondary	1	(20)	12	(31)	28	(35)	9	(27)	21	(47)
Post secondary	1	(20)	13	(34)	26	(32)	12	(36)	13	(29)
<i>Household Income per annum</i>										
\$0 - \$20 000	1	(20)	5	(13)	23	(29)	8	(23)	14	(31)
\$20 001 - \$40 000	3	(60)	23	(60)	45	(56)	23	(66)	24	(53)
>\$40 000	0	(0)	7	(18)	8	(10)	4	(11)	5	(11)
Unknown	1	(20)	3	(8)	4	(5)	0	(0)	2	(4)

*Note: Indicates missing *data*

See Table 4.4 overleaf for details of the mothers self identified language and comprehension skills.

Table 4.4: Frequencies (percentage) of mothers self identified language and comprehension skill level measured over measurement waves at 6-weeks (n=5), 1-year (n=38), 2-years (n=80), 4-years (n=35) and 6-years (n=45) postpartum

Variable	Measurement Wave									
	6-weeks		1-year		2-years		4-years		6-years	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
<i>Languages speak fluently</i>										
English	2	(40)	23	(51)	48	(48)	19	(44)	29	(53)
Samoan	3	(60)	14	(31)	29	(29)	11	(26)	14	(25)
Cook Island Maori	0	(0)	0	(0)	6	(6)	3	(7)	2	(2)
Niuean	0	(0)	0	(0)	1	(1)	1	(2)	1	(1)
Tongan	1	(20)	8	(18)	13	(13)	9	(21)	9	(16)
Other Pacific	0	(0)	0	(0)	2	(2)	0	(0)	0	(0)
<i>“Understand English well?”</i>										
Strongly agree	4	(80)	17	(45)	35	(44)	12	(34)	26	(57)
Agree	1	(20)	17	(45)	42	(52)	11	(31)	13	(30)
Neither disagree or agree	0	(0)	4	(10)	3	(4)	6	(17)	3	(7)
Disagree	0	(0)	0	(0)	0	(0)	6	(17)	2	(4)
Strongly disagree	0	(0)	0	(0)	0	(0)	0	(0)	1	(2)
<i>“Speak English well?”</i>										
A lot	2	(40)	22	(58)	47	(59)	16	(46)	25	(55)
Quite a lot	1	(20)	8	(21)	17	(21)	5	(14)	8	(17)
Somewhat	2	(40)	4	(10)	14	(17)	5	(14)	9	(20)
A little	0	(0)	4	(10)	2	(3)	8	(23)	3	(7)
Not at all	0	(0)	0	(0)	0	(0)	1	(3)	0	(0)

Note: For languages spoken fluently some participants were able to speak one or more of the languages listed fluently and hence the total percentage being greater than the total. The 2-years and 4-years measurement waves use baseline 6-week data for all figures (including language fluency), for the 6-year measurement wave baseline figures are only used for language fluency.

4.3.2 Frequencies of injury events by inpatient and outpatient status

The listed NHI injury event total included 72 (60%) inpatient and 48 (40%) outpatient events, whereas the PIF Study injury event total included 55 (40%) inpatient and 84 (60%) outpatient events (see Figure 4.2). A statistically significant greater number of inpatient injury events were listed in the NHI database than in the PIF Study questionnaires and conversely a statistically greater number of outpatient injury events were reported in the PIF Study questionnaires than listed in the NHI database (Fisher's exact test $P=0.001$).

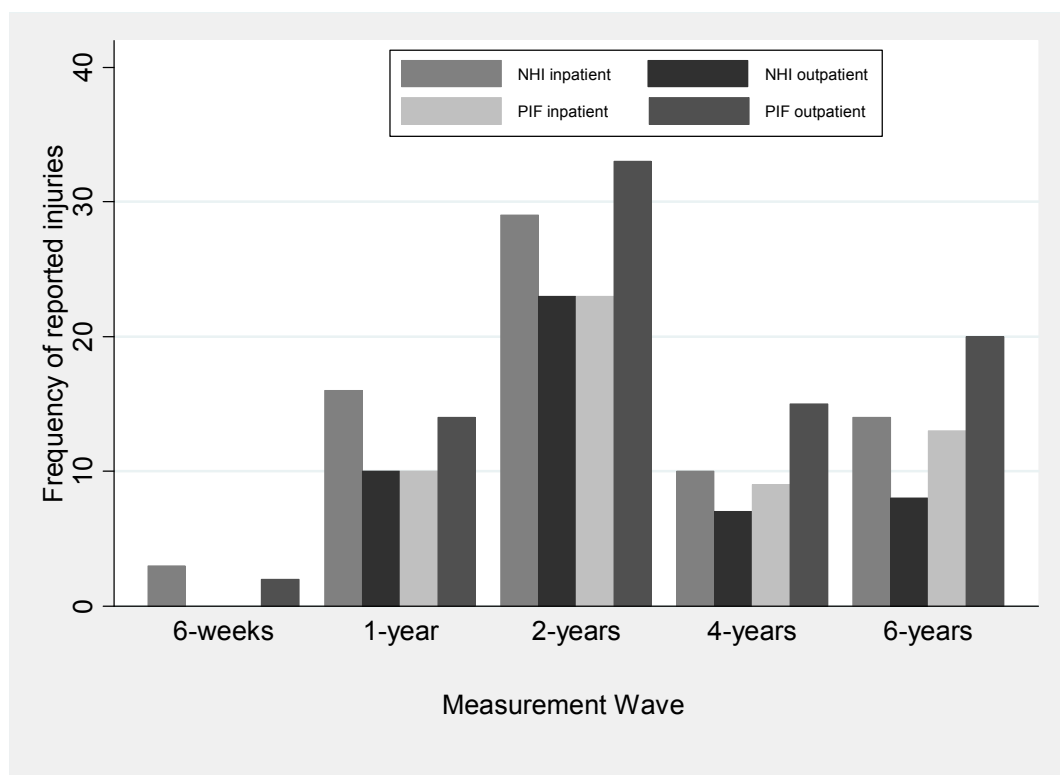


Figure 4.2: *Frequencies of reported inpatient and outpatient injury events by NHI and PIF Study at study measurement waves*

A total of 3 inpatient injury events at 6-weeks, 16 at 1-year, 29 at 2-years, 10 at 4-years and 14 inpatient injuries at the 6-years measurement waves, were listed in the NHI database. While no outpatient injury events occurred at 6-weeks, 10 at 1-year, 23 at 2-years, 7 at 4-years and 8 outpatient injuries at the 6-years measurement waves were also listed in the NHI database. In comparison no inpatient injury events at 6-weeks, 10 at 1-year, 23 at 2-years, 9 at 4-years and 13 inpatient injuries at the 6-years measurement waves were reported in the PIF Study questionnaire. A further total of 2

outpatient injury events at 6-weeks, 14 at 1-year, 33 at 2-years, 15 at 4-years and 20 outpatient injuries at the 6-years measurement waves, were also reported in the PIF Study questionnaire. Overall no statistically significant difference was found between the number of NHI database injury listings and the reports of injuries in the PIF Study questionnaire over all measurement waves (Fisher's exact test 6-weeks $P=1.00$, 1-year $P=0.26$, 2-years $P=0.18$, 4-years $P=0.21$, and 6-years $P=0.10$, respectively).

It should be noted that a total of one outpatient and seven inpatient listed injury NHI events, over the study time period, were amalgamated by the researcher from two separate events into one injury event. This occurred where a second injury event commenced immediately following an initial event, either within the same date of commencement or following an inpatient stay for the same reason i.e. injury event. Subsequently any non injury event which followed an injury event was not included as an injury event per se.

4.3.3 Identification of injury occurrences in PIF Study questionnaires unrelated to medical attendance questions

Specific injury information elicited in the PIF Study questionnaire prior to the questions on hospital, OPC or EC medical attendance revealed that participants who despite not stating they had a medical attendance or did not indicate the attendance was injury related, had earlier identified an injury or injuries had occurred in the corresponding time period (refer to Appendix 4 for specific details of injury related questions). Table 4.5 shows the reporting of the injury related events captured in the PIF Study questionnaires (prior to the medical attendance questions) from an overall perspective of potential match versus non matching categories, over all measurement waves.

A general trend of injuries within the no report categories shows a higher proportion of injuries within the 'no report categories with previous injury report' than the 'no report categories with no previous injury report'. A X^2 goodness of fit test was undertaken to show if this apparent higher level of mothers in the no report category who had previously reported injuries was due to chance alone. The goodness of fit tests revealed that in both of the reported variables, namely the 'overall injury events' and the 'PIF Study outpatient injury events', both independently were found to have a statistically higher proportion $P<0.001$ of individuals who had previously reported an injury in the PIF Study questionnaires, than those who had not previously reported an

injury. This shows that although the injury event listed in the NHI database or reported in the PIF questionnaire was in a 'no report' category the mother had previously stated the child had experienced an injury.

Table 4.5: Frequency of PIF primary caregivers reporting child injury events in the PIF Study questionnaires or NHI database prior to the medical attendance questions over events

Variable	Measurement Wave											
	6-weeks		1-year		2-years		4-years		6-years		Total	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
<i>Overall injury events</i>												
Match categories with previous injury report	0	(0)	20	(40)	44	(41)	8	(19)	12	(22)	84	(32)
Match categories with no previous injury report	0	(0)	0	(0)	0	(0)	0	(0)	2	(4)	2	(1)
No report categories with previous injury report	2	(40)	21	(42)	45	(42)	27	(66)	31	(56)	126	(49)
No report categories with no previous injury report	3	(60)	9	(18)	19	(18)	6	(15)	10	(18)	47	(18)
Total overall injury events	5		50		108		41		55		259	
<i>PIF Study outpatient injury events</i>												
Match categories with previous injury report	0	(0)	3	(21)	9	(23)	0	(0)	1	(5)	13	(15)
Match categories with no previous injury report	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)
No report categories with previous injury report	0	(0)	10	(74)	24	(77)	15	(100)	18	(90)	67	(80)
No report categories with no previous injury report	2	(100)	1	(5)	0	(0)	0	(0)	1	(5)	4	(5)
Total PIF Study outpatient events	2		14		33		15		20		84	

4.3.4 Place of injury visit identified in the PIF Study questionnaires

A total of 147 injury events were initially reported in the PIF Study questionnaires over the 1-year, 2-years and the 4-years measurement waves, although only 104 were included in the final figures and analysis as they were the only injury events that could be captured in the NMDS database. The original identified location for the injury related medical attendance was 4 (2.7%) SPC visits, 13 (8.8%) OPC attendances, 26 (17.7%) EC attendances, and 104 (71%) ED attendances. Table 4.6 presents the frequency of the medical attendance injury event locations over EDs for each measurement wave.

Of particular interest is the fact that in attendances at both SPC and OPC venues, 1 visit (25%) and 9 visits (69%) respectively were identified not to be as a result of a suggestion by a health professional to attend, given that both type of attendances would usually require a prearranged appointment or referral. This may well be dependent on if these services are utilized in the sense of outpatient/day visits or if the participants described the use of hospital services while already at the hospital either during an ED attendance or during an inpatient admission event. The SPC visit was also an inpatient event of a 12 night admission, which was recalled as 20 nights by the mother. Also noteworthy is the fact that 2 (17%) of reported injury related visits to OPCs could have been identified within the ‘time and reason’ category, due to the fact that these matched hospital attendance events captured within the NHI database.

Table 4.7 presents the frequency of the medical attendance injury event locations over OPC attendances, SPC attendances and EC attendances for each measurement wave. These events were reviewed for potential matching to the NHI database listings using the same categories as the ED visits. This was undertaken to illuminate potential or definitive ‘no matches’ that may have been impacted on by differences in the perception of ‘location’ options by the PIF Study participants.

Table 4.6: *Frequencies of location of medical attendance events identified in PIF Study questionnaires, partitioned over potential matching categories in measurement wave's 1-year, 2-years and 4-years*

Injury Event Location	Measurement Wave												Total	
	1-year				2-years				4-years					
	PIF inpatient		PIF outpatient		PIF inpatient		PIF outpatient		PIF inpatient		PIF outpatient			
Matching variable	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
ED Match categories	7	(70)	3	(21)	13	(56)	9	(27)	4	(44)	0	(0)	36	(35)
ED No report categories	3	(30)	11	(79)	10	(43)	24	(73)	5	(11)	15	(100)	68	(65)
Total injury events	10		14		23		33		9		15		104	

Note: ED – emergency department

Table 4.7: *Frequencies of location of medical attendance events identified in PIF questionnaires not captured by NHI database, partitioned over matching categories in measurement waves 1-year, 2-years and 4-years*

	Measurement wave													
	1-year				2-years				4-years				Total	
Injury Event Location	PIF inpatient		PIF outpatient		PIF inpatient		PIF outpatient		PIF inpatient		PIF outpatient			
Matching variable	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
OPC Match categories	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)
OPC No report categories	0	(0)	2	(40)	0	(0)	4	(20)	1	(100)	6	(40)	13	(30)
SPC Match categories	1	(100)	0	(0)	1	(100)	0	(0)	0	(0)	0	(0)	2	(5)
SPC No report categories	0	(0)	0	(0)	0	(0)	2	(10)	0	(0)	0	(0)	2	(5)
EC Match categories	0	(0)	0	(0)	0	(0)	0	(5)	0	(0)	0	(0)	0	(0)
EC No report categories	0	(0)	3	(60)	0	(0)	14	(70)	0	(0)	9	(60)	26	(60)
Total injury events	1		5		1		20		1		15		43	

Note: OPC – Outpatient Clinics; SPC – Specialist visits; EC – Emergency Clinics

4.3.5 Redefined ICD injury code events impact on 'injury versus non injury status' for medical attendance events

Overall a total of 10 ICD redefined code injury events (see Appendix 3) occurred for nine participants, in the NHI database retrieval over measurement waves 1-year, 2-years and 4-years, namely 3, 2 and 5, respectively. A total of 6 inpatient (60%) and 4 outpatient (40%) NHI events initially appeared in the injury category but when re-categorized, using the alternate ICD codes for dichotomising non injury versus injury status, were no longer defined as an injury. Of these 10 separate events, 8 were not reported in the PIF Study questionnaires; with 2 included in the time difference category. The majority of event types were acute (AC), seven in total; with the remaining three events identified as being in the waiting list (WN) category. Of particular note is that 4 individuals (including the participant with 2 separate events) had 54 admissions in total over the three measurement waves, none of these injury events were reported in the PIF Study questionnaires, although non injury events were reported. A limitation of restricted answer space available in the PIF Study questionnaires may have contributed to this apparent under reporting. The PIF Study questionnaires only captured six injury and non injury events in the associated measurement waves and subsequently may not have necessarily captured these events anyway. For the purpose of this study the above injury events are included using the original ICD 10 AM code inclusion criteria for dichotomising of injury/non injury status.

4.3.6 Characteristics of matching category injury events

Overall 259 injury events were recorded of which 86 (33%) are within the potential match categories and 173 (67%) are within the no report categories. Table 4.8 presents the total allocation of injury events within the injury event variable, for all PIF Study reported and NHI listed outpatient and inpatient injury events over all the PIF Study measurement waves. In total 43 (36%) NHI reported injuries were within the match categories and 77 (64%) were in the no report categories. In comparison in the PIF Study questionnaires overall 43 (31%) of injury events were within the match categories and 96 (69%) were in the no report categories. The proportion of total injury events between the listed injury events in the NHI database and the reported injury events in the PIF Study questionnaires were found to not differ significantly (Fisher's exact test $P=0.14$). However a statistically significant difference was found when considering the difference in proportion of the combined 57 listed NHI inpatient injury

events and reported PIF Study questionnaire inpatient injury events within the matching categories and the 70 inpatient combined injury events within the no report categories, with the equivalent combined outpatient events; of which 29 were within the matching categories and 103 in the no report categories (Fisher's exact test $P < 0.001$).

The overview of the allocation of inpatient injury events in each category shows that in the NHI database injury events 27 (37%) were within the matching categories and 45 (63%) of injuries were within the no report categories. Whereas in the PIF Study questionnaires 30 (55%) of inpatient injury events were deemed to match and 25 (45%) of inpatient injury events were within the no report categories, where there was no corresponding record of an injury event. Although no significant association (Fisher's exact test $P = 0.07$) was found between the NHI and PIF Study inpatient injury event allocation between the matching categories.

This was not the case for the NHI and PIF Study outpatient events. Overall a total of 16 (33%) NHI outpatient injury events were within the matching categories and 32 (67%) in the no report categories. In the PIF Study questionnaires a total of 13 (16%) outpatient injury events were within the matching categories, but 71 (84%) of outpatient injury events were found to not be listing the NHI database. A significantly higher proportion of outpatient injury events reported in the PIF Study questionnaire were found to not match the listing in the NHI database (Fisher's exact test $P = 0.03$).

Table 4.8: *Frequencies and percentages of inpatient and outpatient NHI and PIF Study questionnaire event categories*

<i>Matching Variable</i>	<i>NHI Database Inpatient Event</i>		<i>PIF Questionnaire Inpatient Event</i>		<i>NHI Database Outpatient Event</i>		<i>PIF Questionnaire Outpatient Event</i>		<i>Total</i>	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Complete Match	6	(8)	6	(11)	10	(21)	10	(12)	32	(12)
Time Difference	21	(29)	24	(44)	6	(13)	3	(4)	54	(21)
Reason Difference	8	(11)	1	(2)	1	(2)	5	(6)	15	(6)
Time & Reason Difference	6	(8)	3	(5)	3	(6)	0	(0)	12	(5)
No Report	31	(43)	21	(38)	28	(58)	66	(79)	146	(56)
Total	72	(28)	55	(21)	48	(19)	84	(32)	259	

4.3.7 The 'Time Difference' matching category and the time component of the 'Time and Reason' matching category

In the 'time difference' matching category, which shows the injuries that only differ in the stated 'nights in hospital' between the NHI database and PIF Study questionnaires, a total of 24 PIF Study individuals, with 27 matching corresponding event pairs were found over all the measurement waves. All of these individual events corresponded with an inpatient or outpatient injury event by either being also reported in the PIF Study questionnaires or listed in the NHI database. The time difference between the number of nights spent in hospital stated by the PIF Study participants in the questionnaires and the corresponding number of nights spent in hospital listed in the NHI database, revealed a consistently higher number of nights spent in hospital reported in the PIF Study questionnaires reports with a median value of 2 (range: -13, 9).

Figure 4.3 depicts the apparent over estimating of the nights spent in hospital by the PIF Study participants, in comparison to the stated nights spent in hospital identified in the NHI database listings. Overall 22 (81%) of PIF Study reports of 'nights spent in hospital' for injury events were higher, than the matched NHI events stated nights spent in hospital; whereas only 5 (19%) of the NHI injury events reported a higher number of nights spent in hospital in comparison to the matched PIF Study questionnaire injury event. The Wilcoxon signed rank test, a significance test for matched data revealed a statistically significant difference between the nights spent in hospital reported in the PIF Study questionnaires and the corresponding nights spent in hospital listed in the NHI database ($P < 0.001$).

A statistically significant difference (Wilcoxon signed rank test $P = 0.004$) was found between the time spent in hospital listed for NHI inpatient events and PIF Study inpatient injury events, with a higher percentage of a greater number of nights spent in hospital in the PIF Study questionnaires than were listed in the NHI database listings (range: -13,8). Similarly a statistically significant difference was found between the NHI outpatient listed injury events nights spent in hospital and the PIF Study inpatient reported nights spent in hospital (Wilcoxon signed rank test $P = 0.02$), with a higher percentage of nights spent in hospital reported by the PIF Study mothers than were listed in the NHI database (range: 1,9). Whereas no statistically significant difference was found between the NHI inpatient listed nights spent in hospital and the PIF Study outpatient reported nights spent in hospital (Wilcoxon signed rank test $P = 0.08$; range: -1,3).

Of interest is the fact that the two events with the largest time differences, between what the NHI database listing stated and the PIF Study mother reported, which were both excluded from the analysis due to being stated to be ‘specialist’ as the place of visit. Both of these matched in all other ways and would have fitted within the time difference category had specialist visits been included in the NMDS listings. The events were stated in the PIF Study questionnaires to be 42 and 20 nights, but were listed in the NHI database as 26 and 12 nights in respectively.

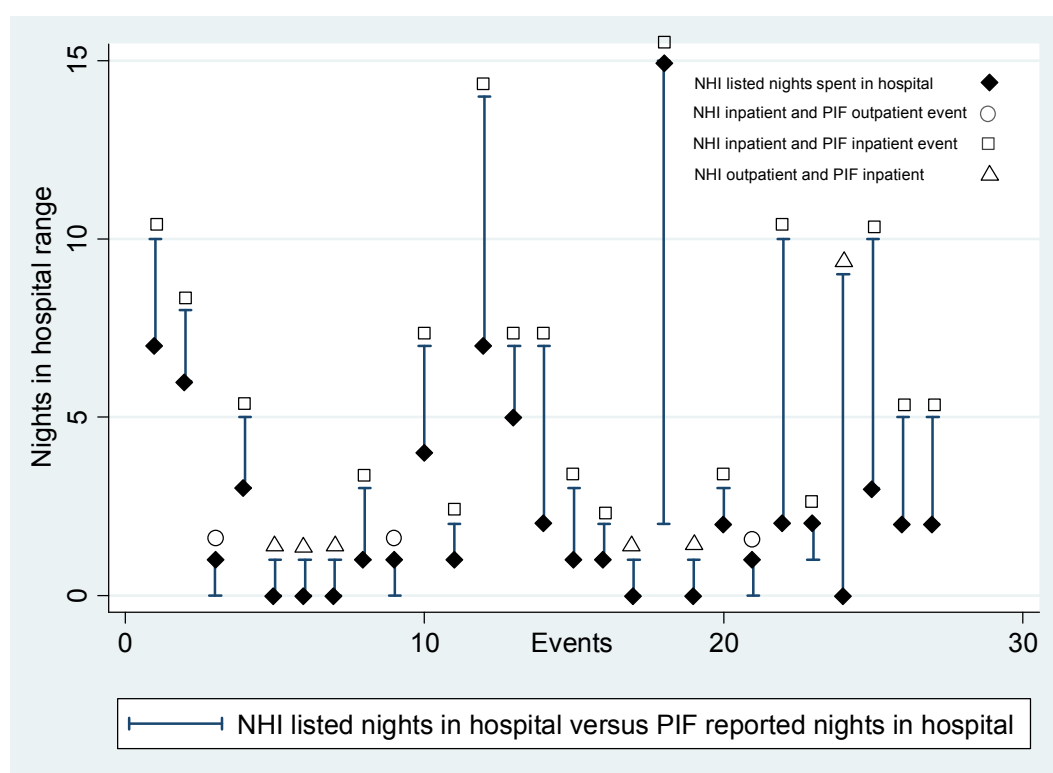


Figure 4.3: Range Plot of Time Differences Shown Between the Number of 'Nights Spent in Hospital' for an Injury Events Listed in the NHI Database Compared to the PIF Study Questionnaire, under the 'Time Difference' Matching Definition.

In the 'time and reason' matching category, a total of 12 separate PIF Study individuals and 12 paired events were documented. Overall the frequency of PIF Study participants reporting a higher number of nights in hospital than recorded in the corresponding NHI event was nine (60%), while in the NHI listings only three (40%) participants showed a greater length of stay in comparison to the PIF Study questionnaire reports with a median value of 1 (range: -7,8). Once again the majority of

events were 0-1 nights or vice versa, with a couple of events with eight and seven nights difference between the NHI listing and the PIF reported nights spent in hospital, no statistical significant difference was found in the nights spent in hospital between the measurement methods (Wilcoxon signed rank test $P=0.12$).

4.3.8 The 'Reason Difference' and 'Time and Reason Difference' matching categories

Overall a total of 12 'time and reason' and 15 'reason' paired events, between the NHI database listings and the PIF Study reports of childhood injuries, occurred over the study period, from a total of 27 individual PIF Study participants. A total of 18 NHI injury events were identified within the 'time and reason' and 'reason' matching categories, which could potentially be matched to non injury PIF Study questionnaire reported events. All these events in the NHI database were identified to be acute (AC) in type, with the exception of one waiting list event (WN). The stated non injury reasons for the event comprised of; 4 breathing symptoms (22%); 6 other significant illnesses (33%); 4 skin conditions (22%); 1 generally unwell (6%); 1 stomach symptom (6%); 1 ear infection (6%); and 1 general symptoms (6%). Of these seven were deemed to be a 'match' and six a 'close match'. As five NHI injury events fell within the 6-year measurement wave no cross checking with the age of the child at the time of event was able to be undertaken.

A total of nine injury events reported in the PIF Study questionnaires appeared to potentially match with non injury NHI events. Due to the dichotomised nature of injury data provided by the NHI database (injury versus non injury status) no non injury reason for the event was able to be elicited and was therefore deemed to be 'unidentifiable'. Of these three were deemed to be a 'match' and two were a 'close match'. Again as four PIF Study injury events fell within the 6-year measurement wave no cross checking with the age of the child at the time of event was able to be undertaken.

4.4 Descriptive Results and Validity Analysis for PIF Study

Measurement Waves

The following sections contain childhood injury information and analyses from each separate measurement wave, commencing with Table 4.9 which shows details of the frequency of PIF Study children's injury events: number of individuals and the corresponding number of events, over the NHI Inpatient, NHI Outpatient, PIF Study Inpatient, and PIF Study Outpatient categories.

Table 4.9: Frequencies of individual-specific overall outpatient and inpatient injuries

Type of reported injury event over each measurement wave	Frequency of injuries for individual children			Total	
	1	2	3	Individuals	Injury Events
6-week					
NHI Inpatient	3	0	0	3	3
NHI Outpatient	0	0	0	0	0
PIF Inpatient	0	0	0	0	0
PIF Outpatient	2	0	0	2	2
1-year					
NHI Inpatient	14	1	0	15	16
NHI Outpatient	10	0	0	10	10
PIF Inpatient	8	1	0	9	10
PIF Outpatient	12	1	0	13	14
2-years					
NHI Inpatient	27	1	0	28	29
NHI Outpatient	21	1	0	22	23
PIF Inpatient	23	0	0	23	23
PIF Outpatient	33	0	0	33	33
4-years					
NHI Inpatient	10	0	0	10	10
NHI Outpatient	7	0	0	7	7
PIF Inpatient	9	0	0	9	9
PIF Outpatient	12	0	1	13	15
6-years					
NHI Inpatient	10	2	0	12	14
NHI Outpatient	8	0	0	8	8
PIF Inpatient	11	1	0	12	13
PIF Outpatient	18	1	0	19	20

4.4.1 6-week measurement wave

The study commenced with a total of 1,354 children in the cohort at the 6-weeks interview, of which 5 (0.36%) either had an inpatient or outpatient injury event reported in the PIF Study questionnaire or listed in the NHI database. The person-specific analyses showed of these, 2 (0.15%) reported at least 1 event in the PIF Study questionnaire, with 2 separate injury events recalled at the 6-weeks measurement wave. See Table 4.10 for details of overall 6-week analyses. In comparison 3 (0.22%) children were listed as having at least 1 injury event in the NHI database, with a total of 3 separate medical attendance events were listed in the NHI database over the same period. Furthermore, with 1,354 children in the cohort at the 6-week measurement wave, this implies no injuries were reported in the PIF Study questionnaire or listed in the NHI database for 1349 (99.6%) of the children.

A total of 5 separate injury events were identified in the PIF Study questionnaire and NHI database, using the complete matching definition. These comprised of 3 separate inpatient and 2 outpatient injury events. Using the event complete and time matching difference resulted in a total of 5 separate injury events. McNemar's test of symmetry found no significant asymmetry in any of the matching variables between the record of child injuries in the PIF Study questionnaires and the NHI database. However despite symmetry being demonstrated the corresponding kappa statistic values revealed a 'poor' level of agreement between the mothers and the NHI database in all categories, using Landis & Koch's (1977) characterisation. A potential impact is the low numbers included for the analysis, with a sample size of five.

Table 4.10:

Frequencies and percentages of PIF self reported questionnaire responses and NHI recorded data of injury events at individual and event levels, together with concordance using the Kappa measure of agreement (κ) and Mc Nemar's test of symmetry P-value at 6-weeks postpartum

Matching variable	Neither PIF nor NHI		PIF only		NHI only		Both PIF and NHI				McNemar's P-value
	n	(%)	n	(%)	n	(%)	n	(%)	κ	(95% CI)	
Person-specific overall	1,349	(99.6)	2	(0.15)	3	(0.22)	0	(0)	0.00	(-0.54,0.50)	1.00
Inpatient person-specific overall	1,351	(99.7)	0	(0)	3	(0.22)	0	(0)	0.00	(0.00,0.00)	0.25
Outpatient person-specific overall	1,352	(99.8)	2	(0.15)	0	(0)	0	(0)	0.00	(0.00,0.00)	0.50
Event complete matching	1,349	(99.6)	2	(0.15)	3	(0.22)	0	(0)	0.00	(-0.50,0.54)	1.00
Inpatient event complete matching	1,351	(99.7)	0	(0)	3	(0.22)	0	(0)	0.00	(0.00,0.00)	0.25
Outpatient event complete matching	1,352	(99.8)	2	(0.15)	0	(0)	0	(0)	0.00	(0.07,0.18)	0.50
Event complete and time matching difference	1,349	(99.6)	2	(0.15)	3	(0.22)	0	(0)	0.00	(-0.05,0.05)	1.00

4.4.2 1-year measurement wave

Overall there were 1,205 children in the cohort at the 1-year measurement wave of which 38 (3.1%) PIF Study mothers either reported an inpatient or outpatient injury event in the PIF Study questionnaire, or listed in the NHI database. The person specific analysis showed of these, 22 (1.8%) reported at least one injury event in the PIF Study questionnaire, with 24 separate events recalled at the 1-year measurement wave (See Table 4.11). In the same time period 24 (2.0%) children were listed as having at least one injury event in the NHI database, with a total of 26 separate medical attendance events. Furthermore, with 1,205 children in the cohort at the 1-year measurement wave, this implies we have no injuries reported in the PIF Study questionnaire or listed in the NHI database for 1,167 (97%) of the children. A total of 21 (1.7%) individual children were reported to have had inpatient injury events and 21 (1.7%) reported outpatient injury events at the 1-year measurement.

A total of 48 separate matching injury events were identified using the event complete matching definition in the PIF Study questionnaire and NHI database. These comprised of both 26 separate inpatient and 22 outpatient events. A total of 40 separate injury events were identified using the 'event complete and time difference' matching over the PIF Study questionnaires and NHI database. The inclusion of the 'time difference' category into the matching category resulted in a higher number of injury events subsequently 'matching' in the 1-year measurement wave, from 2 matching injury events to 10 matching injury events over the same time period. McNemar's test of symmetry no significant asymmetry between the reporting of injuries in the PIF Study questionnaires and the NHI database listings.

However the kappa statistic demonstrated a poor level of agreement for inpatient event complete matching ($\kappa = 0.00$). Slight levels of agreement were found for outpatient person-specific overall; event complete matching; and outpatient event complete matching variables (κ range 0.06 to 0.17). The highest level of agreement was found for the person-specific overall inpatient person-specific overall; and for the event complete and time matching difference variables (κ range 0.24-0.39) constituting a fair level of agreement using Landis and Koch's characterisation (1977).

Table 4.11:

Frequencies and percentages of PIF self reported questionnaire responses and NHI recorded data of injury events at individual and event levels, together with concordance using the kappa measure of agreement (κ) and Mc Nemar's test of symmetry P-value at 1 year postpartum

Matching variable	Neither PIF nor NHI		PIF only		NHI only		Both PIF and NHI				McNemar's P-value
	n	(%)	n	(%)	n	(%)	n	(%)	κ	(95% CI)	
Person-specific overall	1,167	(97)	14	(1.2)	16	(1.4)	8	(0.7)	0.34	(0.28,0.39)	0.86
Inpatient person-specific overall	1,184	(98)	6	(0.5)	12	(1.0)	3	(0.3)	0.24	(0.19,0.30)	0.24
Outpatient person- specific overall	1,184	(98)	11	(0.9)	8	(0.7)	2	(0.2)	0.17	(0.11,0.22)	0.65
Event complete matching	1,167	(97)	22	(1.8)	24	(2.0)	2	(0.2)	0.06	(-0.005,0.11)	0.90
Inpatient event complete matching	1,184	(98)	10	(0.8)	16	(1.3)	0	(0.0)	0.00	(-0.66,0.04)	0.33
Outpatient event complete matching	1,184	(98)	12	(1.0)	8	(0.7)	2	(0.2)	0.16	(0.10,0.21)	0.50
Event complete and time matching difference	1,167	(97)	14	(1.2)	16	(1.3)	10	(0.8)	0.39	(0.33,0.44)	0.86

4.4.3 2-year measurement wave

Overall there were 1,137 children in the cohort at the 2-year measurement wave of which 80 (7.0%) PIF Study mothers either reported an inpatient or outpatient injury event for their child in the PIF Study questionnaire or an injury was reported in the NHI database. The person specific analysis showed of these, 54 PIF Study children were reported to have had at least one injury event in the PIF Study questionnaire, with 56 separate events recalled at the two year measurement wave. See Table 4.12 for details of overall 2-year analyses. In comparison for the same time period 47 children were listed as having at least one injury event in the NHI database, with a total of 52 separate medical attendance events were listed in the NHI database over the same period. Furthermore, with 1,137 children in the cohort at the 2-year measurement wave, this implies we have no injuries reported in the PIF Study questionnaire or listed in the NHI database for 1,057 (93%) of the children.

A total of 39 (3.4%) children were reported to have had inpatient injury events and 47 (4.1%) reported outpatient injury events at the 2-year measurement wave. The event complete matching definition illuminated a total of 96 separate injury events in the PIF Study questionnaire and NHI database, comprised of 48 inpatient and 48 outpatient injury events. The combination of including the event complete and time difference in the 2-year analysis resulted in a total of 86 separate injury events.

The inclusion of the 'time difference' category into the matching category resulted in a higher number of injury events subsequently 'matching' in the 2-year measurement wave, from 12 matching injury events to 22 matching injury events over the same time period. McNemar's test of symmetry no significant asymmetry between the reporting of injuries in the PIF Study questionnaires and the NHI database listings. The kappa statistic demonstrated the lowest level of agreement 'slight' between the two measurement tools, namely the PIF Study questionnaire and the NHI database for the event complete matching overall ($\kappa = 0.18$) and the inpatient event complete matching ($\kappa = 0.13$). A fair level of agreement was found in the person-specific overall; the outpatient person-specific; the outpatient event complete matching; and the event complete and time matching variable (κ range = 0.27 to 0.39). While a moderate level of agreement was found for the inpatient person-specific analysis ($\kappa = 0.46$).

Table 4.12

Frequencies and percentages of PIF self reported questionnaire responses and NHI recorded data of injury events at individual and event levels, together with concordance using the kappa measure of agreement (κ) and Mc Nemar's test of symmetry P-value at 2-year postpartum

Matching variable	Neither PIF nor NHI		PIF only		NHI only		Both PIF and NHI		κ	(95% CI)	McNemar's P-value
	n	(%)	n	(%)	n	(%)	n	(%)			
Person-specific overall	1,057	(93)	33	(2.9)	26	(2.3)	21	(1.8)	0.39	(0.33,0.45)	0.43
Inpatient person-specific overall	1,098	(97)	11	(1.0)	16	(1.4)	12	(1.1)	0.46	(0.40,0.52)	0.44
Outpatient person- specific overall	1,090	(96)	25	(2.2)	14	(1.2)	8	(0.7)	0.27	(0.22,0.33)	0.11
Event complete matching	1,057	(93)	44	(3.9)	40	(3.5)	12	(1.1)	0.18	(0.13,0.24)	0.74
Inpatient event complete matching	1,098	(97)	19	(1.7)	25	(2.2)	4	(0.3)	0.13	(0.08,0.19)	0.45
Outpatient event complete matching	1,090	(96)	25	(2.2)	15	(1.3)	8	(0.7)	0.27	(0.21,0.33)	0.15
Event complete and time matching difference	1,057	(93)	34	(3.0)	30	(2.6)	22	(1.9)	0.38	(0.32,0.44)	0.71

4.4.4 4-year measurement wave

Overall there were 1,048 children in the cohort at the 4-years measurement wave of which 35 (3.3%) PIF Study mothers either reported an inpatient or outpatient injury event for their child in the PIF Study questionnaire or an injury was reported for their child in the NHI database. The person specific analysis showed of these, 22 reported at least one event in the PIF Study questionnaire, with 24 separate events reported overall. See Table 4.13 for details of overall 4-years analyses. In comparison for the same time period 17 children were listed as having one injury event in the NHI database, with a total of 17 separate medical attendance events listed in the NHI database. A total of 16 (1.5%) individual children were reported to have had inpatient injury events and 20 (1.9%) reported outpatient injury events at the 4-years measurement. Furthermore, with 1,048 children in the cohort at the 4-years measurement wave, this implies we have no injuries reported in the PIF Study questionnaire or listed in the NHI database for 1013 (96.6%) of the children.

A total of 39 separate injury events were reported in the PIF Study questionnaire and NHI database at the 4-years measurement wave, using the complete matching definition. These comprised of 17 (1.6%) separate inpatient and 22 (2.1%) outpatient injury events. A total of 37 separate events occurred in the 4-years measurement phase when 'time difference' was included along with the 'complete matching' variable to find the number of events that had the potential to match between the NHI database and the PIF Study questionnaires. The inclusion of the 'time difference' category into the matching category resulted in a higher number of injury events subsequently 'matching' in the 4-years measurement wave, from 2 matching injury events to 4 matching injury events over the same time period.

McNemar's test of symmetry found no significant asymmetry between the reporting of injuries in the PIF Study questionnaires and the NHI database listings. The lowest levels of concordance between the NHI database and PIF Study questionnaires was found to be 'poor' for both outpatient person-specific overall and outpatient event complete matching ($\kappa = 0.00$, respectively). With the highest level of agreement 'fair' found in the Inpatient person-specific overall variable ($\kappa = 0.31$). All other variables were found to be 'slight', including; person-specific overall; event complete matching; inpatient complete matching; and event complete and time matching difference (κ range = 0.08 to 0.19).

Table 4.13:

Frequencies and percentages of PIF self reported questionnaire responses and NHI recorded data of injury events at individual and event levels, together with concordance using the kappa measure of agreement (κ) and Mc Nemar's test of symmetry P-value at 4-years postpartum

Matching variable	Neither PIF nor NHI		PIF only		NHI only		Both PIF and NHI				McNemar's P-value
	n	(%)	n	(%)	n	(%)	n	(%)	κ	(95% CI)	
Person-specific overall	1,013	(97)	18	(1.7)	13	(1.2)	4	(0.4)	0.19	(0.13,0.25)	0.47
Inpatient person-specific overall	1,032	(98)	6	(0.6)	7	(0.7)	3	(0.3)	0.31	(0.25,0.37)	1.00
Outpatient person- specific overall	1,028	(98)	13	(1.2)	7	(0.7)	0	(0.0)	0.00	(-0.07,0.05)	0.26
Event complete matching	1,013	(97)	22	(2.1)	15	(1.4)	2	(0.2)	0.08	(0.02,0.14)	0.32
Inpatient event complete matching	1,032	(98)	7	(0.7)	8	(0.7)	2	(0.2)	0.20	(0.14,0.26)	1.00
Outpatient event complete matching	1,028	(98)	15	(1.4)	7	(0.7)	0	(0.0)	0.00	(-0.06,0.05)	0.13
Event complete and time matching difference	1,013	(97)	20	(1.9)	13	(1.2)	4	(0.4)	0.18	(0.12,0.24)	0.30

4.4.5 6-year measurement wave

With 996 children in the cohort at the 6-year measurement wave, 45 (4.5%) PIF Study mothers either reported an injury or their child was listed in the NHI database as having had a medical attendance due to an injury. The person specific analysis showed of these, 30 (3%) mothers reported at least one injury event in the PIF Study questionnaire, resulting in 33 separate injury events captured in the PIF Study questionnaire. While 20 (2%) children were reported to have had an injury event in the NHI database, with 22 separate events listed over the corresponding period. This implies a total of 4.5% of the cohort at the 6-years measurement wave experienced an injury event over the preceding year, conversely 951 (95.5%) are not reported to have had a medical attendance injury event. A total of 20 (2%) children reported an inpatient injury event and 27 (2.7%) were listed as having an outpatient injury event in the NHI database.

A total of 55 separate injury events were identified using the complete matching definition in the PIF Study questionnaire and the NHI database. Of these 28 separate injury events were outpatient and 27 injury events were inpatient in nature. Of particular interest is the fact that although no ‘complete matches’ were found in this measurement wave between the PIF Study questionnaire reported injury events and the NHI database listed injury events, once events that only differed in time were considered as ‘complete matches’ seven events were then found to match between the PIF Study questionnaires and the NHI database. The corresponding kappa statistic value also reflected an improved beyond chance agreement level between the PIF Study questionnaires and the NHI database from $\kappa = -0.03$ (poor agreement) to $\kappa = 0.20$ (slight agreement).

A significant level of asymmetry was found in the inpatient person-specific overall ($P=0.05$) and outpatient event complete matching ($P=0.04$) categories, with a significantly higher number of events were reported in the PIF Study questionnaires than captured in the NHI database. Given that 35 McNemar's tests overall were performed, with the significance level of $\alpha=0.05$, one would expect 5% to be significantly asymmetrical by chance alone. This would result in an expected level of $35 \times 0.05 = 1.75$ significant tests would be expected to show significant asymmetry by chance alone. Given that these two McNemar's tests were found to show significant asymmetry, the results may be spurious and a type I error has occurred.

Despite symmetry being found between the childhood injuries reported in the NHI database listings and the reports of childhood injuries in the PIF Study questionnaires; the following matching categories had ‘poor’ kappa levels ($\kappa= 0.00$) inpatient person-specific; overall inpatient event complete matching; event complete matching; and outpatient event complete matching categories. See Table 4.14 for details of overall 6-year analyses overleaf.

Table 4.14: *Frequencies and percentages of PIF self reported questionnaire responses and NHI recorded data of injury events at individual and event Levels, together with concordance using the kappa measure of agreement (κ) and Mc Nemar's test of symmetry P-value at 6- year postpartum*

Matching variable	Neither PIF nor NHI		PIF only		NHI only		Both PIF and NHI				McNemar's P-value
	n	(%)	n	(%)	n	(%)	n	(%)	κ	(95% CI)	
Person-specific overall	951	(95)	25	(2.5)	15	(1.5)	5	(0.5)	0.18	(0.12,0.24)	0.15
Inpatient person-specific overall	976	(98)	8	(0.8)	8	(0.8)	4	(0.4)	0.33	(0.26,0.39)	1.00
Outpatient person-specific overall	969	(97)	19	(1.9)	8	(0.8)	0	(0)	0.00	(-0.68,0.45)	0.05
Event complete matching	951	(95)	33	(3.3)	22	(2.2)	0	(0)	0.00	(-0.87,0.03)	0.18
Inpatient event complete matching	976	(98)	13	(1.3)	14	(1.4)	0	(0)	0.00	(-0.07,0.05)	1.00
Outpatient event complete matching	969	(97)	20	(2.0)	8	(0.8)	0	(0)	0.00	(-0.07,0.04)	0.04
Event complete and time matching difference	951	(95)	26	(2.7)	15	(1.6)	7	(0.7)	0.20	(0.14,0.26)	0.13

4.5 Summary

Due to the modest number of injuries captured and modest kappa values (shown below in Table 4.15) found in all the measurement waves, showing low levels of concordance between the PIF Study reported childhood injuries and the NHI listed child injuries; no secondary analysis was undertaken to identify any levels of differential recall over socio-demographic variables. It was considered to proceed with further analysis on the basis that the two measurement methods were not consistent in their identification of childhood injuries and the inability to establish which, if either, method was more accurate was thus hampered. Measurement error may have occurred in either method.

Table 4.15: Levels of agreement, using Landis and Koch's characterisation of kappa, between the NHI database listings and the PIF questionnaire reporting of childhood injuries, over the matching variable injury categories; for each measurement wave.

Kappa Matching Variable	6-weeks	1-year	2-years	4-years	6-years
Person-specific overall	Poor	Fair	Fair	Slight	Slight
Inpatient person-specific overall	Poor	Fair	Moderate	Fair	Fair
Outpatient person-specific overall	Poor	Slight	Fair	Poor	Poor *
Event complete matching	Poor	Slight	Slight	Slight	Poor
Inpatient event complete matching	Poor	Poor	Slight	Slight	Poor
Outpatient event complete matching	Poor	Slight	Fair	Poor	Poor *
Event complete and time matching difference	Poor	Fair	Fair	Slight	Slight

*indicates asymmetry present between the NHI database injury event listings and the PIF Study questionnaire reported injury events

5: Discussion

5.1 Introduction

The discussion chapter seeks to review the findings of the study and contextualize these findings within other research studies. Results will be considered against existing knowledge bases pertaining to the multiplicity of factors that may have contributed to the ability to match the childhood injuries reported in the PIF questionnaire to those listed in the NHI database. Initially the research questions will be reviewed and the key findings presented. The following sections will highlight the factors inherent within both the NHI database and the PIF Study, along with the processes of combining the two measurement methods together, which may have impacted on the matching outcomes. The crucial role and impact of measurement issues will be discussed, along with factors that have been shown to produce bias in similar studies and may have contributed to bias in the present study. Finally an overview of pertinent issues and study limitations will be presented to conclude the chapter, along with recommendations for future research and an overall assessment of the use of maternal recall in the use of childhood injuries.

5.2 Summary of Results

The study sought to identify if the use of maternal recall within the PIF questionnaires to identify childhood injuries attendances at public hospital facilities provided a valid and reliable picture of the extent of childhood injuries. Each child's injuries were matched to a criterion measure, the NHI database listings of childhood injuries linked to each child and conversely these listings were reviewed to see if they matched to the childhood injuries listed in the PIF questionnaires. Kappa statistics and McNemar's test of symmetry were undertaken to establish reliability and validity respectively.

5.2.1 Reliability

Overall the reliability was found to be modest over all matching variable categories for both inpatient and outpatient injury events, when reviewed both on an individual and at an event level. Kappa values ranged from $\kappa = 0.00$ in the 6-week event complete and time matching difference category, to $\kappa = 0.46$ in the 2-year inpatient specific overall category. Using Landis & Koch's characterisation of the level of agreement between the reported PIF childhood injuries in the questionnaires and the listed NHI childhood injuries these constituted a 'poor' and 'moderate' level of

agreement (Landis & Koch, 1977). Using Landis and Koch's characterization the following numbers of each characterisation category were found: 14 at the poor level, 11 at the slight level, 9 at the fair level and 1 at the moderate level. It is noted that none of the 2-year kappa analyses were found to be of a poor level of agreement, considering this was the measurement wave with the highest sample of injured children (n=80).

In comparing these results to the studies reviewed earlier the kappa values had ranged between a fair level and substantial level of agreement for emergency department attendances and hospital admissions (D'Souza-Vazirani et al., 2005; Ungar et al., 2007). In relation to the range of recall for other medical related events the kappa values ranged from slight to substantial (Kennan et al., 2007; Pless & Pless, 1995; Ungar et al., 2007). As acknowledged the studies employed a variety of research methodologies, with some being more robust than others. The range of kappa's were fairly similar between these studies and the present study, given the variation in methodological approaches. Although certainly more kappa values fell within the moderate and substantial levels of agreement in the reviewed studies, the impact of larger sample sizes and the obtaining of ethical consent may have contributed to these kappa values.

Conversely it was likely the 6-week analyses were impacted on by the very small dataset of 5 children, resulted in limited statistical power to reveal the underlying picture. The 6-year analyses whilst found to have four 'poor' levels of agreement over the variables, was also likely to be biased due to the inability to separate emergency clinic visits from hospital visits for the analysis, as had been done over the previous measurement waves; and the NMDS database only capturing outpatient ED events where actual treatment time is over three hours in length.

5.2.2 Validity

Likewise the 6-year Mc Nemar's test of symmetry found asymmetry between the NHI database listings of childhood injury and the PIF reported childhood injuries, in the direction towards the NHI database under reporting childhood injuries. Due to the low number of injury events captured in the cohort and NHI database, in addition to the low reliability demonstrated, no analyses were undertaken to review the impact of potential compounding variables on the matching levels found between the NHI database listings of childhood injuries and the PIF reported childhood injuries. Overall it is anticipated the low sample numbers may have impacted on the analyses precision,

as well as the potential of measurement bias and error being present both within the NHI database information and the PIF questionnaires data, and study protocols that will be discussed in the following sections. The undertaking of longitudinal statistical analysis such as generalized estimating equations could have been used to explore these relationships, but this was beyond the scope of the present study. In comparison to the PIF Study, where no evidence was found of mother's under-reporting hospital attendance for childhood injuries, this was not the case in the reviewed studies. Several studies concluded that mothers had under-reported medical attendance events (Stone et al., 2006; Kennan et al., 2007). As both of these groups were with families identified to be at risk, the ability to generalize their findings may be limited.

5.2.3 Differences

It was noticed an increase in the number of reported injury events were reported by PIF participants at the 2-year measurement wave and 6-year measurement waves. The 2-year measurement wave corresponds to the time period where children are becoming more ambulant and therefore the risk of injuring themselves may therefore be enhanced (Flavin, Dostaler, Simpson, & Pickett, 2006; WHO & UNICEF, 2008). The question can be posed 'why the increase in the 6-year measurement wave?' Parity, as previously identified has been associated with lower agreement rates between medical records and maternal reports and if the child is the oldest the potential for more accurate recall as the child ages is possible (Elkadry et al., 2003). Although the impact of the outpatient attendances not being captured, as they had been prior, had the potential to impact on the level of concordance as well.

It is also plausible that the mothers were primed to be attentive to their child's health through participation in the study and familiarity with the injury/illness and medical attendance questions may have impacted on this apparent higher level of reporting. These phenomena could also be due to the severity level of childhood injuries changing over time leading to a greater severity of injury, cueing more accurate recall from the mothers (WHO & UNICEF, 2008). These are all issues that would benefit from being explored in other research projects.

Despite the low concordance found overall, a statistically significant level of mothers ($P < 0.001$) who fell within the 'no report' matching category, had previously indicated their child had experienced an injury over the corresponding time period. This suggests that the lack of recall of the injury medical attendance event was not in an

attempt to state their child had not had an injury per se, but more likely to be a recall issue or possibly as a result of the staging of the injury question first. Given that no statistically significant level of under-reporting of events was found by the PIF participants this suggests that the level of overall recall bias was low.

5.2.4 Potential limitations of cross checking NHI numbers

Whilst considerable care and diligence was given to matching the PIF NHI numbers to the individual NHI numbers held by the NHI, there is a possibility that some of the NHI codes were not in fact a match as was concluded by the identified matching procedure. Refer to Table 3.1 for the original matching rules (Taylor, S., personal communication, October 19, 2009). As the rule set 1 to 3 inclusive contains birth NHI, gender, DOB, surname, and versions of first names, one could assume that potential mismatching would have been more likely to occur within rule 4 to rule A1.

Further examination of the PIF children whose NHI code was matched under the stated rules 4 to A1, found 38 of the PIF children with injury events fell within these NHI code matching rules, with the rest falling within NHI code matching rule 1 to rule 3 inclusive. See Table 5.1 for the distribution of the children whose NHI codes were matched using rules 4 – A1, that fell within matching and non matching categories. Of the 31 events that fell within the no match categories, 12 were within the PIF outpatient questionnaires, so may not have been captured by the NHI database. This suggests that the NHI code number matching procedures may have been successful, given that when the outpatient events that fell in the no match categories, are not considered, both the events that fell in the ‘matching’ and ‘no report’ categories were similar in numbers.

Table 5.1: Child matching NHI code rules by categories of events over the matching categories and non matching categories over all measurement waves

Rule	Matching Categories	No Match Categories	Total
<i>Rule 4:</i> Birth NHI, Gender, DOB, Surname (excl. twins)	8	12	16
<i>Rule 5:</i> Birth NHI, Gender, DOB, First name (excl. twins)	4	15	17
<i>Rule 6:</i> Birth NHI, Gender, DOB, First name (twins)	0	0	0
<i>Rule 7:</i> Birth NHI, Gender, DOB, Middle name	0	1	1
<i>Rule 8:</i> Gender, DOB, Surname, Initial	0	0	0
<i>Rule A1:</i> Manually matched	4	3	4
Total	16	31	38

5.3 Limitations and Considerations of the use of NHI Data on the Matching Outcome

The NHI databases proved to be very complex and considerably more difficult and time consuming to extract accurate information to match with the PIF questionnaires reported injury events than had been anticipated. Such challenges are recognized in the literature and attributed to the databases being established to meet a multiplicity of needs, including for administrative and funding purposes, rather than a primary focus on data for researchers needs (O'Malley et al., 2005). Limitations in the way that outpatient events were captured inconsistently in the NMDS by different DHBs around New Zealand, along with varying timing of their implementations may have affected the matching processes undertaken. Conversely, the NMDS databases prime purpose is not to capture outpatient events, particularly with the advent of the NN PAC database in 2006. But despite this, given little asymmetry was found between the NHI listings and the PIF reported injuries, it is however plausible that had the NHI database captured all ED visits that there may have been more asymmetry found in the direction of the PIF participants, but obviously this is not able to be established conclusively. In other words had the NMDS database shown all outpatient visits and the PIF mothers had not reported the greater majority of these events, there could have been

asymmetry, with the NHI database reporting more outpatient events than the PIF mothers. Consequently this could impact on the significance levels found with McNemar's test of symmetry.

The exclusion of using the NNPAC data due to a multitude of factors, including the low number of injury events pertaining to the PIF children, was unfortunate but necessary. The NNPAC database also commenced in July 2006 and subsequently was in the initial stages of integration and development within both the DHB's and the NZHIS in the study time period, which subsequently may have given rise to inconsistencies. Despite this with its development over time, it will become an invaluable tool to use in research. However with the proviso that there is consistency in its application, which has not been the case for the NMDS.

Publishing of regular audit data on coding practices and quality of the information contained within the databases from service providers would also be helpful for researchers, especially when using the NHI database as a criterion value on which judgements will be made on the efficacy of an alternate measurement method, as has been the case with the present study. The limited amount of such audit information available and limited researchers driving quality assurance of coding accuracy has been recognised by injury prevention researchers in the past. Conversely acknowledgement is given that audits do occur but are not readily available to the general public (McKenzie et al., 2009; Cryer et al., 2004).

The researcher was able to locate one published report from the 2001/2002, undertaken by the NZHIS on the accuracy of the ICD coding for 2708 events, over 10 sites. It found 16% of coded medical events required some changes. On average 11% of principal diagnoses were changed, with 15% of external codes also being recoded (NZHIS, 2002). With the present study not utilizing any other codes apart from the primary diagnosis it could be easy to assume that with the use of only a dichotomised injury versus non injury status that little error may have occurred. A review of coding accuracy under ICD-10-AM, for principal injury diagnosis was undertaken by Davie et al. (2008), using NMDS hospital discharges from July 2001 to June 2004, shed light on the fact that errors in coding may be present. An independent senior coder found from a sample of 1,800 injury events, 37 (2%) of primary diagnoses were not coded as an injury at the primary diagnosis level. So there is an identified potential for some of the PIF reported injury events that were found to not match, to fall within this category.

However the quality of the data that the NHI database contains is not only dependent on the NZHIS procedures or coders who enter the information into the ICD-10-AM-1 format for the NHI database use, but is dependent on the practices and the communications between the child and their caregiver and the hospital staff. These very practices by hospital staff and communication issues may very well have impacted on the ability of the PIF mothers to accurately recall the injury events for the PIF questionnaire completion.

5.4 Limitations and Consideration of the PIF Questionnaires on the Matching Outcome

Evidence obtained in the study suggest that the mothers may have misinterpreted some of the questions which ultimately could have impacted on the matching process, leading to the potential for information bias, and/or misclassification being present. This was highlighted in occurrences such as when mothers were asked to identify if the hospital visit had been suggested and they answered ‘no’ for outpatient clinic events or specialist visits, when this would normally be the case; and in attendances which were either a hospital event described as non injury in nature in the PIF questionnaires but matched an injury event in the NHI database or vice versa. Despite due consideration given to the measurement processes undertaken within the PIF Study , the possibility exists that practices inherent within the study may have impacted on the ability for the injury events to match those listed in the NHI database. These may include the impact of comprehension of questions on the matching outcomes.

Prior to the PIF studies initial questionnaire development for the ‘First Two Years of Life study’ focus groups were held with Pacific mothers to explore the main areas of concern for families and their children over the first two years of life. Subsequently this information informed the development of the 6-week questionnaire. Once the questionnaire was developed a pilot study of 50 mothers of Pacific infants at Middlemore Hospital (who were not actual cohort mothers) was undertaken to pilot the data collection procedures and the questionnaires.

Advice and guidance has been sought from relevant stakeholders regarding the main issues for Pacific families, seeking to reflect the developmental stages of life for the children, in each measurement wave. Informally the mothers have given feedback on the method of interviewing and clarity of the questions to PIF Study team staff. The PIF management team have actively discussed issues and any questions the interviewers

might have or pose, in an endeavour to review questions used. This feedback has resulted in refinements where necessary, with the exception of questions in the standardized instruments. The PIF team staff members have specialist protocol groups who work on their area of expertise and interest sourcing recognized and standardized measurement tools where possible to integrate into future questionnaires. Once consensus is reached within these groups the ideas are presented to the overall PIF team for feedback on the actual questions. The protocols are then reviewed by the Pacific People's Advisory Board to gain their opinions and to respond to any concerns they may have, adjusting questionnaires if required once a consensus is reached. These review processes continue to be implemented and are ongoing in nature (Paterson, J., personal communication, July 12, 2010).

The medical attendance and injury questions used to measure the injury and medical attendance events were not standardized questions and some aspects did change over time from the 6-week questionnaire. Whilst the inclusion of PIF staff, interested parties, community members and the crucial role of the PPAB in guiding the studies progression and developing questionnaires is undeniably important, the socio demographical characteristics of the sample group may vary from these individuals and hence their interpretations of the questions may also.

Other studies advocate the use of focus groups with individuals similar to the participants to assess any potential for alternate views or differing levels of comprehension in questions prior to them being used in questionnaires, which may impact on the accuracy of the answer given (Golding, Pembrey, Jones, & the ALSPAC study team, 2001). But once again this also needs to be balanced in practical terms against how many new questions are being included in any upcoming questionnaire. In the PIF Study the majority of questions have remained unaltered and hence should remain acceptable and appropriate to the PIF participants. The manner in which the interviews are undertaken, with mothers matched where possible with ethnic specific interviewers who are conversant in their own language seeks to alleviate any misinterpretations that may occur due to language issues. Along with the use of researcher assisted interviewer techniques, as are practised in the PIF Study, this seeks to alleviate the majority of potential problems that may occur due to comprehension. These dual approaches are certainly advocated as a necessary approach when working with Pacific peoples and culturally diverse groups (Anea., et al 2001; Warnecke et al., 1997). It is also anticipated that for those whose English levels were limited on

commencement of the study, with increasing length of stay in New Zealand, their English should have improved.

5.5 Combined Issues Between the Two Measurement Methods

The complexities of combining the two datasets may have impacted on the matching process. Children with multiple admissions were all captured in the NHI database listings, but as there was a restriction in the number of events able to be recorded in the PIF questionnaires it was often impossible to relate which event associated with which. It is plausible that with an increasing number of hospital events requiring recall, the greater the potential that the ability to recall the events as separate entities and accurately will be compromised.

Time differences also posed an interesting dilemma in the review of the data, due to the complexities of defining what constitutes a ‘night in’ between a hospital administrative system and ‘parents perceptions’. For the purposes of the NMDS database the ‘length of stay’ is described as ‘including a midnight’. Of note is the fact that 11 (28%) of the ‘time difference’ and ‘time and reason’ injury events were in the range of 0 to 1 night, or vice versa. Of these 3 (27%) events were identified as PIF outpatient events and 8 (73%) as NHI inpatient or NHI outpatient events. This result is puzzling but consistent with the significantly higher reporting of nights spent in hospital by PIF participants than recorded in the NHI database. One would also anticipate a flow on effect from this timing issue to impact on hospital inpatient stays of greater length as well. The redefined ICD-10-AM codes showed possible discrepancies between what the medical terminology defines as an injury and what parents might define an injury to be, given that only 2 of these events were in a matching category, within ‘time difference’, the rest were not reported.

5.6 The Potential Impact of the ‘No Consent’ Approach to Study and Implications for Other Similar Studies

Clearly there may be implications with this study, that moderate kappa values were influenced by the non consent approach undertaken. This may have resulted in a larger sample than what might have been obtained if consent was obtained. Although conversely not all PIF participants agreed to have their medical records reviewed in the overall cohort and their characteristics could differ once again from those included in the sub study. As previously acknowledged the low level of injuries would have also contributed as well, regardless of the consent approach. The researcher found a dearth

of studies that sort to review the maternal reports of childhood injuries with medical records or health database information. The possibility exists that more studies have been undertaken but are not in the public domain, either through publication bias or researchers being reluctant to report what they may perceive to be ‘negative findings’. This could be due to the perceived likelihood of decreased respect of their study, potential ramifications on funding, or discrimination against the groups the participants are chosen to represent.

5.7 Study Limitations

In regards to the overall PIF cohort study there are several limitations which are likely to have impacted on this sub-study. The inability to include those who declined their medical records to be reviewed may have resulted in a biased sample for this sub study, although the numbers were low. The study relied on previously gained information which was subject to recall bias due to the nature of self and proxy reported information.

Non standardized injury measurement tools were used in the PIF Study. The presence of ethnic specific interviewers sought to facilitate culturally appropriate interview techniques and comprehension of the questions asked; however despite this and prompt cues given on what constituted an injury the mothers perception of an injury could have still varied. Restrictions in the number of answers in the questionnaire, for each measurement wave, for medical events affected the ability of those with a greater number of events to identify these events – accordingly this may have affected the ability for these individuals’ medical attendance events to match. Due to inherent limitations in the 6-year PIF questionnaire there was no ability to cross check age at medical attendance event or place of attendance, which may have impacted on the accuracy of the matching process. Finally due to the longitudinal nature of repeated assessments over measurement waves, it is plausible this may have impacted on recall due to similar questions being asked.

Limitations also were influenced by NHI processes and the provision of data from the NHI database. There are inconsistencies in the manner in which the NMDS captures outpatient visits, with more than three hour’s treatment time being deemed to constitute an inpatient admission. Although this practice is not uniformly undertaken in New Zealand, variations in the capture of these events could have impacted on the matching process. The NNPA database commenced in July 2006, so all outpatient

attendances are only available after this time. In relation to using the NHI database information as the criterion standard to act as the 'gold standard measurement', on which to compare the maternal reports of childhood injury, the researcher acknowledges that the NHI database has not been validated to act in this role.

Initially it was requested that the following ICD-10-AM injury codes be removed from the redefined ICD code injury events, 'insect bites, toxic effects of seafood and noxious substances eaten, and toxic effects of contact with venomous animals in the 4-year and 6-year injury categories due to additional prompts being given in these measurement waves. This was not practical and was not undertaken. This may have impacted on inaccurate display of some of the restricted ICD code events as supplied by the NHI in these measurement waves. In relation to the medical attendance event identification at the NHI, it was anticipated that the request for dichotomised injury/non injury status at the ICD-10-AM-1 primary diagnosis level, would reduce the potential for inaccurate definitions of an injury obtained from the NHI dataset, but the possibility that this occurred cannot be ruled out.

The differences between the 'parents perception' of what constituted an injury compared to the 'ICD injury code definitions' may have resulted in differences between the concordance between the PIF participant reported injury events and those listed in the NHI database. Ideally a focus group would have been undertaken to discuss mothers perceptions of what ICD injury code events would be perceived as being an injury or not, but resource issues, including time limitations on the study precluded this from occurring. Of note is the fact that the researcher was unable to locate literature on this topic.

More general factors that may be limitations include the impact of the ethical approach undertaken in the matching of NHI numbers, which restricted confirmation of details from either the parents or secondary sources i.e. GP. Furthermore errors in coding and in data entry for both the NHI dataset and PIF Study cannot be ruled out. Finally from a statistical point of view the small sample cell size for both the kappa and Mc Nemar's statistics, particularly at the 6-week measurement wave could impact on the accuracy of analysis, however there was no way to rectify or predict this as these were the levels of injuries found.

5.8 Future Research Recommendations

In light of experiences gained during this research study, literature reviewed and areas in the data that illuminate factors that potentially impacted on why the injury events did not match between the two measurement sources, the recommendations for future research and questionnaire development for child injury questions include.

1. Exploration of the differences between parent's perceptions of what constitutes an injury/illness and how this may impact on studies seeking to compare parent or proxy reports of childhood data, to the definitions contained in medical records or health databases.
2. The use of representative focus groups of Pacific mothers, with a variety of socio-demographic characteristics, to complement present consultative methods for questionnaire development in the PIF Study is suggested; to ensure questions asked are salient and the language used elicits the information desired, with terminologies understood by participants.
3. Both quantitative and qualitative research would be beneficial to gain further understanding of the health literacy levels of Pacific peoples living in New Zealand. This would be helpful both in terms of gaining knowledge on how best health researchers can pose questions on health in research but also on health care utilization and adherence to treatment regimes among Pacific peoples.
4. Further investigation into the reasons for the significantly higher reported nights spent in hospital by the PIF participants is warranted to investigate the potential for over reporting of other phenomena assessed in the questionnaires as well.
5. A formal investigation into the reliability of the use of maternal recall over each time period is warranted given the previously acknowledged changes in the level of reporting of the PIF participants over the five measurement waves. The use generalized estimating equations in longitudinal studies to establish reliability of maternal recall over time is advocated.
6. More reliability and validity studies should be undertaken in New Zealand, in a variety of domains to ensure that information researchers base their ultimate recommendations on is accurate.

7. The development of international standardized and recognized proxy/self report forms for parents to be used in child injury research is advocated.

In retrospect the decision to use the NHI database as the ‘gold standard’ or criterion measure on which to compare the maternal self report of childhood injury was not without question. As the study has progressed, both in terms of undertaking the literature review and in trying to tease the information out of both respective measurement tools, it became apparent that one was not comparing ‘like with like’. But conversely this decision was not totally unfounded given that the literature has revealed problems and complexities with other forms of measuring childhood injuries as well (Cummings et al., 1995; O, Malley et al., 2005). In trying to maintain credibility from both a scientific perspective by ensuring the information elicited within the PIF Study is as accurate as possible; and an ethical perspective of using participant’s time and knowledge wisely, one has to balance this with the upholding of cultural considerations.

As Del Boca and Noll (2000) state “Self report data are inherently neither valid nor invalid, but vary with the personal circumstances of the respondent and the methodological sophistication of the data gatherer” (p. S358). They advocate the important issues to focus on should infact be what conditions are conducive to facilitating accurate recall from participants and what procedures foster valid responses, which is advocated in other injury and non injury research alike.

6: Conclusion

The primary purpose of this study was to assess the accuracy of obtaining information on childhood injury within the PIF Study by the use of maternal recall, by comparing the reports given to hospital childhood injury data held in the NHI database. The results overall suggest that the use of maternal recall in measuring childhood injuries was found to be a valid measurement tool, given no systematic under-reporting of childhood injuries by PIF mothers was found. However the level of concordance found between the PIF mothers and the NHI database and examination of the responses given, does provide some evidence that questions may have been misinterpreted. This suggests continued vigilance and development is necessary in designing the most effective questions to elicit accurate information about child injuries and corresponding medical attendance events. The results obtained appear consistent with the limited research undertaken in this field in other similar studies (D'Souza-Vazirani et al., 2005; Rice et al., 2006; Tate et al., 2006; Ungar et al., 2007).

Overall it was not possible to state which measurement tool held the most accurate findings. Whilst it could be easy to assume that the NHI database held the most accurate information, to our knowledge this has not been proven and challenges do exist to the use of such health databases to assess the accuracy of maternal/parent proxy reports of child health medical attendance events, as a 'gold standard', along with medical records themselves from where the data originally is derived from. Conversely conflicting evidence has been presented around the accuracy of maternal reports of childhood events including the recall of childhood injuries.

In the absence of certainty that the NHI database or in fact that maternal self report is an accurate method, one must assume that both have their respective roles to play in improving knowledge on childhood injuries. Both with inherent strengths and weaknesses as identified through the information presented. Whilst the extent of the lack of concordance between the NHI database and the PIF reporting of childhood injuries was not anticipated, insights gained during the process are useful for guiding different ways to approach seeking childhood injury information in the future.

Philips (2003) challenges

Quantifying uncertainty does not create uncertainty. It merely measures and reports that uncertainty that is always there. This is not a matter of making a trade-off, of accurately reporting uncertainty at the expense of reducing the value of our findings. Quite the contrary, quantified uncertainty better describes what we know, and thus can facilitate better decisions, suggest improvements in our methods, and help direct new research to where it provides the most benefit. (p. 465)

The PIF Study will continue to build on the strong relationships already developed with the Pacific community and with the research participants to ensure the questions and methods used to gain information are effective. As acknowledged the results from the study suggest participants may have misinterpreted some of the illness and medical attendance questions. This is in concordance with other studies that have found lower levels of agreement between proxy reports of childhood and maternal medical events for mothers with immigrant status and to whom English is a second language (Tate et al., 2006; Ungar et al., 2007).

The question 'is there a gold standard' criterion measure on which to compare child injury events remains. There is no easy answer to this question, but the developing focus on improving data collection and quality in childhood injury should assist in building the knowledge base in this field. As sectors work increasingly together in a co-operative manner, all seeking to effect positive changes on the injury rates of children, a difference is likely to be made. The researcher believes this study has demonstrated how the responsible use of data, in partnership with the NZHIS can facilitate a wider understanding of research findings and facilitate more effective research in the future; all of which can only strengthen the knowledge base to contribute to injury prevention initiatives. As acknowledged by Cameron, Purdie, Kliwer, Wajda, and McClure (2007) a partnership between the organisations involved in data linkage is crucial to ensure the design and development of such databases are accommodating to both the needs of administrators and epidemiological researchers alike. The researcher acknowledges that the judicious use of data from the NZHIS has facilitated this process and views their role in collaborative research studies to be pivotal in fostering robust scientific enquiry into the future.

Previously gained research knowledge, when combined with Pacific knowledge that the participants and their respective communities can bring, can only enhance the measurement methods already utilized by the PIF Study. The researcher believes this offers the best pathway in the future to ensure information gained, not just on childhood injuries, but on children's health overall is as accurate as possible. This is ultimately applicable not just for the PIF Study but any research study that is using questionnaires as a method for gaining information on the health status of children. After all at the heart of the study are the participants themselves and it is to them who we need to turn to enquire about how to improve the methods we use to gain information from them, after all who else is in a better position to tell us.

For now the question of 'is there a gold standard?' criterion measure on which to compare child injury events remains elusive. Ultimately the researcher believes it is imperative for all parties to work collaboratively to maximize their respective strengths to improve child health and wellbeing. This brings us back to the start of this journey and Kokeny's (2006) statement that "the health status of a society is an imprint of a given period" (p. 133). Only time will tell in the future how our present societies efforts to reduce the number of childhood injuries that occur on a day to day basis will be viewed. It is imperative that we continue to refine our ability to capture adequate data on childhood injuries, not just for the children of today, but for the generations of children to follow.

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APPENDICES

APPENDIX 1: NORTHERN X REGIONAL ETHICS COMMITTEE STUDY APPROVAL LETTER



Northern X Regional Ethics Committee
Ministry of Health
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650 Great South Road, Penrose
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Wellesley Street, Auckland
Phone (09) 580 9105
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14 July 2009

Ms Heather Robertson
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Dear Heather

NTX/09/73/EXP

A validity and reliability study of maternal reports of childhood injuries that result in hospital attendance or admission, do they match National Health Index database records?

Principal Investigator:
Supervisors:

Ms Heather Robertson
Prof Philip Schluter, Mr Gerhard Sundborn

Thank you for your response and the amendment received 13 July 2009. The above study has been given ethical approval by the Deputy Chairperson of the **Northern X Regional Ethics Committee** under delegated authority.

Approved Documents

- Protocol (undated, received 3/07/09)

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report

The study is approved until **14 July 2010**. A final report is required at the end of the study and a form to assist with this is available at <http://www.ethicscommittees.health.govt.nz>. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments

It is also a condition of approval that the Committee is advised if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Cheh Chua (Ms)
Assistant Administrator
Northern X Regional Ethics Committee

APPENDIX 2: ETHICS APPROVAL FROM AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE (AUTEC)



MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Philip Schluter
From: **Madeline Banda** Executive Secretary, AUTEC
Date: 14 August 2009
Subject: Ethics Application Number 09/173 A validity and reliability study of maternal reports of childhood injuries that result in hospital attendance or admission, do they match National Health Index database records?

Dear Philip

I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTEC) approved your ethics application at their meeting on 10 August 2009. Your application is now approved for a period of three years until 10 August 2012.

I advise that as part of the ethics approval process, you are required to submit to AUTEC the following:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/research/research-ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 10 August 2012;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/research-ethics>. This report is to be submitted either when the approval expires on 10 August 2012 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this. Also, if your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within that jurisdiction.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at ethics@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the AUTEC and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Madeline Banda'.

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

CC: Heather.Robertson@roberts@aut.ac.nz

APPENDIX 3: ‘SPECIALIZED INJURY EVENT FLAG’ ICD-10-AM 1ST EDITION CODES EXCLUDED FOR DICHOTOMISING NON INJURY VERSUS INJURY STATUS

Blisters

S0002	Superficial injury of scalp, blister
S0022	Other superficial injuries of eyelid and periocular area, blister
S0032	Superficial injury of nose, blister
S0042	Superficial injury of ear, blister
S0052	Superficial injury of lip and oral cavity, blister
S0082	Superficial injury of other parts of head, blister
S0092	Superficial injury of head, part unspecified, blister
S1012	Other and unspecified superficial injuries of throat, blister
S1082	Superficial injury of other parts of neck, blister
S1093	Superficial injury of neck, part unspecified, insect bite
S2012	Other and unspecified superficial injuries of breast, blister
S2032	Other superficial injuries of front wall of thorax, blister
S2042	Other superficial injuries of back wall of thorax, blister
S2082	Superficial injury of other and unspecified parts of thorax, blister
S3082	Other superficial injuries of abdomen, lower back and pelvis, blister
S3092	Superficial injury of abdomen, lower back and pelvis, part unspecified, blister
S4082	Blister of shoulder and upper arm
S5082	Blister of forearm
S6082	Blister of wrist and hand
S7082	Blister of hip and thigh
S8082	Blister of lower leg
S9082	Blister of ankle and foot
T0902	Blister of trunk, level unspecified
T1102	Blister of upper limb, level unspecified
T1302	Blister of lower limb, level unspecified
T1402	Blister of unspecified body region

Insect Bites

S0003	Superficial injury of scalp, insect bite
S0023	Other superficial injuries of eyelid and periocular area, insect bite
S0033	Superficial injury of nose, insect bite
S0043	Superficial injury of ear, insect bite
S0053	Superficial injury of lip and oral cavity, insect bite
S0083	Superficial injury of other parts of head, insect bite
S0093	Superficial injury of head, part unspecified, insect bite
S1013	Other and unspecified superficial injuries of throat, insect bite
S1083	Superficial injury of other parts of neck, insect bite
S1093	Superficial injury of neck, part unspecified, insect bite
S2013	Other and unspecified superficial injuries of breast, insect bite
S2033	Other superficial injuries of front wall of thorax, insect bite
S2043	Other superficial injuries of back wall of thorax, insect bite
S2083	Superficial injury of other and unspecified parts of thorax, insect bite

S3083	Other superficial injuries of abdomen, lower back and pelvis, insect bite
S3093	Superficial injury of abdomen, lower back and pelvis, part unspecified, insect bite
S4083	Insect bite of shoulder and upper arm
S5083	Insect bite of forearm
S6083	Insect bite of wrist and hand
S7083	Insect bite of hip and thigh
S8083	Insect bite of lower leg
S9083	Insect bite of ankle and foot
T0903	Insect bite of trunk, level unspecified
T1103	Insect bite of upper limb, level unspecified
T1303	Insect bite of lower limb, level unspecified
T1403	Insect bite of unspecified body region

Toxic effect of noxious substances eaten as seafood

T610	Ciguatera fish poisoning
T611	Scombroid fish poisoning
T612	Other fish and shellfish poisoning
T618	Toxic effect of other seafoods
T619	Toxic effect of unspecified seafood

Toxic effect of noxious substances eaten as food

T620	Ingested mushrooms
T621	Ingested berries
T622	Other ingested (parts of) plant(s)
T628	Other specified noxious substances eaten as food
T629	Noxious substance eaten as food, unspecified

Toxic effect of contact with venomous animals

T630	Snake venom
T631	Venom of other reptiles
T632	Venom of scorpion
T633	Venom of spider
T634	Venom of other arthropods
T635	Toxic effect of contact with fish
T636	Toxic effect of contact with other marine animals
T638	Toxic effect of contact with other venomous animals
T639	Toxic effect of contact with unspecified venomous animal
T64	Toxic effect of aflatoxin and other mycotoxin food contaminants

Heatstroke and sunstroke

T670	Heatstroke and sunstroke
T671	Heat syncope
T672	Heat cramp
T673	Heat exhaustion, anhydrotic
T674	Heat exhaustion due to salt depletion

T675	Heat exhaustion, unspecified
T676	Heat fatigue, transient
T677	Heat oedema
T678	Other effects of heat and light
T679	Effect of heat and light, unspecified

Other effects of reduced temperature

T68	Hypothermia
T690	Immersion hand and foot
T691	Chilblains
T698	Other specified effects of reduced temperature
T699	Effect of reduced temperature, unspecified

Effects of other deprivation

T730	Effects of hunger
T731	Effects of thirst
T732	Exhaustion due to exposure
T733	Exhaustion due to excessive exertion
T738	Other effects of deprivation
T739	Effect of deprivation, unspecified

Effects of other external causes

T753	Motion sickness
T758	Other specified effects of external causes – abnormal gravitation (G forces), weightlessness

Effects of air pressure and water pressure

T700	Otitic barotraumas –effect of change in ambient atmospheric or water pressure on ears
T701	Sinus barotraumas – effect of change in ambient atmospheric pressure on sinuses
T702	Other and unspecified effects of high altitude – alpine, anorexia, mountain sickness...
T703	Caisson disease [decompression sickness]
T704	Effects of high-pressure fluids – traumatic jet injection
T709	Effect of air pressure and water pressure, unspecified

Complications of surgical and medical care, not elsewhere classified (T80-T88.9)

T800	Air embolism following infusion, transfusion and therapeutic injection
T801	Vascular complications following infusion, transfusion and therapeutic injection
T802	Infections following infusion, transfusion and therapeutic injection
T803	ABO incompatibility reaction
T804	Rh incompatibility reaction
T805	Anaphylactic shock due to serum

T806	Other serum reactions
T808	Other complications following infusion, transfusion and therapeutic injection
T809	Unspecified complication following infusion, transfusion and therapeutic injection
T810	Haemorrhage and haematoma complicating a procedure, not elsewhere classified
T811	Shock during or resulting from a procedure, not elsewhere classified
T812	Accidental puncture and laceration during a procedure, not elsewhere classified
T813	Disruption of operation wound, not elsewhere classified
T814	Infection following a procedure, not elsewhere classified
T815	Foreign body accidentally left in body cavity or operation wound following a procedure
T816	Acute reaction to foreign substance accidentally left during a procedure
T817	Vascular complications following a procedure, not elsewhere classified
T818	Other complications of procedures, not elsewhere classified
T819	Unspecified complication of procedure
T820	Mechanical complication of heart valve prosthesis
T821	Mechanical complication of cardiac electronic device
T822	Mechanical complication of coronary artery bypass and valve grafts
T823	Mechanical complication of other vascular grafts
T824	Mechanical complication of vascular dialysis catheter
T825	Mechanical complication of other cardiac and vascular devices and implants
T826	Infection and inflammatory reaction due to cardiac valve prosthesis
T827	Infection and inflammatory reaction due to other cardiac and vascular devices, implants and grafts
T828	Other complications of cardiac and vascular prosthetic devices, implants and grafts
T829	Unspecified complication of cardiac and vascular prosthetic device, implant and graft
T830	Mechanical complication of urinary (indwelling) catheter
T831	Mechanical complication of other urinary devices and implants
T832	Mechanical complication of graft of urinary organ
T833	Mechanical complication of intrauterine contraceptive device
T834	Mechanical complication of other prosthetic devices, implants and grafts in genital tract
T835	Infection and inflammatory reaction due to prosthetic device, implant and graft in urinary system
T836	Infection and inflammatory reaction due to prosthetic device, implant and graft in genital tract
T838	Other complications of genitourinary prosthetic devices, implants and grafts
T839	Unspecified complication of genitourinary prosthetic device, implant and graft
T840	Mechanical complication of internal joint prosthesis
T841	Mechanical complication of internal fixation device of bones of limb
T842	Mechanical complication of internal fixation device of other bones
T843	Mechanical complication of other bone devices, implants and grafts
T844	Mechanical complication of other internal orthopaedic devices, implants and grafts
T845	Infection and inflammatory reaction due to internal joint prosthesis
T846	Infection and inflammatory reaction due to internal fixation device [any site]
T847	Infection and inflammatory reaction due to other internal orthopaedic prosthetic devices, implants and grafts
T848	Other complications of internal orthopaedic prosthetic devices, implants and grafts
T849	Unspecified complication of internal orthopaedic prosthetic device, implant and graft

T850	Mechanical complication of ventricular intracranial (communicating) shunt
T851	Mechanical complication of implanted electronic stimulator of nervous system
T852	Mechanical complication of intraocular lens
T853	Mechanical complication of other ocular prosthetic devices, implants and grafts
T854	Mechanical complication of breast prosthesis and implant
T855	Mechanical complication of gastrointestinal prosthetic devices, implants and grafts
T856	Mechanical complication of other specified internal prosthetic devices, implants and grafts
T8571	Infection and inflammatory reaction due to peritoneal dialysis catheter
T8578	Infection and inflammatory reaction due to other internal prosthetic devices, implants and grafts
T8581	Other complications due to nervous system device, implant or graft
T8588	Other complications of internal prosthetic device, implant or graft, NEC
T859	Unspecified complication of internal prosthetic device, implant and graft
T860	Bone-marrow transplant rejection
T861	Kidney transplant failure and rejection
T862	Heart transplant failure and rejection
T863	Heart-lung transplant failure and rejection
T864	Liver transplant failure and rejection
T8681	Lung transplant failure and rejection
T8682	Pancreas transplant failure and rejection
T8688	Failure and rejection of other transplanted organs and tissues
T869	Failure and rejection of unspecified transplanted organ and tissue
T870	Complications of reattached (part of) upper extremity
T871	Complications of reattached (part of) lower extremity
T872	Complications of other reattached body part
T873	Neuroma of amputation stump
T874	Infection of amputation stump
T875	Necrosis of amputation stump
T876	Other and unspecified complications of amputation stump
T880	Infection following immunization
T881	Other complications following immunization, not elsewhere classified
T882	Shock due to anaesthesia
T883	Malignant hyperthermia due to anaesthesia
T884	Failed or difficult intubation
T885	Other complications of anaesthesia
T886	Anaphylactic shock due to adverse effect of correct drug or medicament properly administered
T887	Unspecified adverse effect of drug or medicament
T888	Other specified complications of surgical and medical care, not elsewhere classified
T889	Complication of surgical and medical care, unspecified

APPENDIX 4: PIF STUDY QUESTIONNAIRES ‘INJURY AND ILLNESS QUESTIONS’ OVER EACH MEASUREMENT WAVE

6- week questionnaire

Since the baby was born, has s/he had any of the following symptoms? ‘No/Yes’

answer option

- Been generally unwell? Fever, not feeding, not his usual self, not active, not alert or playful?
- Problems with breathing? Cough, noisy breathing, breath holding spells, runny nose, wheeze?
- Stomach symptoms? Severe green vomiting, diarrhoea or both, blood in faeces, ulcers in mouth?
- Skin conditions? Rashes or sores?
- Urinary Symptoms? Infection of bladder or urine e.g. Blood in urine, changes in frequency of urination?
- Neurological symptoms? Convulsions or fits?
- Injuries? Falls, fractures, cuts etc?
- Eye Infections?
- Ear Infections?
- Other significant illness?

1-year questionnaire

Since we last saw you, has your child had any of the following symptoms? ‘No/Yes’

answer option

- Been generally unwell? Fever, not feeding, not his usual self, not active, not alert or playful?
- Problems with breathing? - Cough, runny nose, noisy fast breathing, breath holding spells, wheeze?
- Stomach symptoms? Sore tummy, severe (green) vomiting, diarrhoea or both, blood in faeces, ulcers in mouth?
- Skin conditions? Rashes or sores?
- Urinary Symptoms? Infection of bladder or urine e.g. blood in urine, changes in frequency of urination?
- Neurological symptoms? Convulsions or fits?

- Injuries? Falls, fractures/broken bones, cuts etc?
- Eye Infections (e.g. sticky eyes) or Vision problems (e.g. squinting eyes)?
- Ear Infections?
- Other significant illness?

During the first year of life, children often have accidents around the home. How often has your child had the following accidents? *'Number of times' answer option*

- Serious falls (resulting in injury such as cuts or broken bones)
- Burns/scalds (e.g. from hot water, fire, hot elements on stove)
- Poisoning (e.g. from the household cleaners, medications)
- Choking (e.g. from small objects or toys)

2-years questionnaire

Since we last saw you when your child was 12 months old, has your child had any of the following symptoms? *Number of times answer option*

- Been generally unwell? Fever, not feeding, not his usual self, not active, not alert or playful?
- Problems with breathing? - cough, runny nose, noisy fast breathing, wheeze
- Stomach symptoms? Sore tummy, severe (green) vomiting, diarrhoea or both, blood in faeces, ulcers in mouth?
- Skin conditions? Rashes or sores?
- Urinary Symptoms? Infection of bladder or urine e.g. Blood in urine, changes in frequency of urination?
- Neurological symptoms? Convulsions or fits?
- Injuries? *Number of times answer option*
 - Serious falls (resulting in injury such as cuts or broken bones)
 - Burns/scalds (e.g. from hot water, fire, hot elements on stove)
 - Poisoning (e.g. from household cleaners, medications)
 - Choking (e.g. from small objects or toys)
 - Car/bicycle accident
 - Other accidents
- Eye Infections (e.g. sticky eyes) or vision problems (e.g. squinting eyes)?
- Ear Infections (e.g. glue ear)?
- Other significant illness?

4-years and 6-years questionnaires

In the last 12 months has your child had any of the following symptoms? ‘*Number of times*’ answer option

- Been generally unwell? Fever, not feeding, not his usual self, not active, not alert or playful?
- Problems with breathing? - cough, runny nose, noisy fast breathing, wheeze?
- Stomach symptoms? Sore tummy, severe (green) vomiting, diarrhoea or both, blood in faeces, ulcers in mouth?
- Skin conditions Rashes - No Yes, Sores?
- Urinary Symptoms? Infection of bladder or urine egg. Blood in urine, changes in frequency of urination?
- Neurological symptoms? Convulsions or fits?
- Injuries?
 - Contact with an object (e.g. Hit with a ball, walked into wall, struck by falling object)?
 - Application of bodily force (e.g. Hit by a person)?
 - Crushing (e.g. Crushed beneath something, in a door)?
 - Falling (e.g. Off table, off stairs, out of window)?
 - Penetrating force (e.g. Cutting with a knife, animal, insect or human bite)?
 - Threats to breathing (e.g. Compression of the chest, drowning)?
 - Burns/scalds (e.g. Hot water, fire, hot elements on stove & cold burns, e.g. ice)?
 - A motor vehicle accident (being in a motor vehicle crash, run over by a vehicle including a bicycle)?
 - Poisoning (e.g. Accidental overdose of a drug, ingestion of a toxic substance, ingestion of a substance harmful to a child)?
 - Ingestion of a foreign body (e.g. A toy, shell or something swallowed)?
 - Any other cause (e.g. An injury caused by anything not set out above)?
- Eye Infections (e.g. sticky eyes) or vision problems (e.g. squinting eyes)?
- Ear Infections (e.g. glue ear)?
- Other significant illness?

APPENDIX 5: PIF STUDY QUESTIONNAIRE ‘MEDICAL ATTENDANCE QUESTIONS’ OVER EACH MEASUREMENT WAVE

6- week questionnaire

How many time has the baby attended or been admitted to a HOSPITAL? *'Number of times' answer option.*

4 visits recorded with the following details

- Age of baby? weeks
- Reason for visit? (from previous illness/injury identification questions above)
- Treatment?
- Number of nights in hospital?

1-year questionnaire

How many times has the child attended or been admitted to a HOSPITAL or EMERGENCY CLINIC or been referred to a specialist? *'Number of times' answer option*

6 visits recorded with the following details

- Child age – months?
- Main reason? (see table below for options)
- Which department did you go to?
 - Emergency department?
 - Outpatient clinic?
 - Other?
- Specialist?
- Emergency clinic – not major hospital?
- Number of nights in hospital?
- For this visit, did your doctor or other health professional suggest you take the baby to hospital (or specialist emergency clinic)? *(Yes/No answer option)*

Reason for taking child to hospital/specialist/clinic

Reason	Examples
General symptoms	fever, not feeding, not his usual self, not active, not alert or playful
Breathing symptoms	cough, noisy fast breathing, breath holding spells, runny nose, wheeze
Stomach symptoms	sore tummy, severe (green) vomiting, diarrhoea or both, blood in faeces, ulcers in mouth
Skin conditions	rashes or sores
Urinary Symptoms	infection of bladder or urine e.g. blood in urine, changes in frequency of urination
Neurological symptoms	convulsions or fits
Injuries	falls, fractures/broken bones, cuts, burns, scalds
Eye Infections or problems	sticky eyes or squinting eyes
Ear Infections	
Other significant illness	

2-years and 4-years questionnaire

2-years - Since we last visited you when you child was 12 months old, how many times has the child attended or been admitted to a HOSPITAL or EMERGENCY CLINIC or been referred to a specialist? *'Number of times' answer option*

4-years – In the last 12 months how many times has the child attended or been admitted to a HOSPITAL or EMERGENCY CLINIC or been referred to a specialist? *'Number of times' answer option*

6 visits recorded in each measurement wave with the following details

- Child age – months?
- Main reason? (see table below for options)
- Which department did you go to?
 - Emergency department
 - Outpatient clinic
 - Other

- Specialist
- Emergency clinic – not major hospital
- Number of nights in hospital
- For this visit, did your doctor or other health professional suggest you take the baby to hospital (or specialist emergency clinic)? (*Yes/No answer option*)

Reason for taking child to hospital/specialist/clinic (used for year 2, year 4 and year 6 measurement wave)

Reason	Examples
General symptoms	fever, not feeding, not his usual self, not active, not alert or playful
Breathing symptoms	cough, noisy fast breathing, breath holding spells, runny nose, wheeze
Stomach symptoms	sore tummy, severe (green) vomiting, diarrhoea or both, blood in faeces, ulcers in mouth
Skin conditions	rashes or sores
Urinary Symptoms	infection of bladder or urine e.g. blood in urine, changes in frequency of urination
Neurological symptoms	convulsions or fits
Injuries	falls, fractures/broken bones, cuts, burns, scalds
Eye Infections or problems	sticky eyes or squinting eyes, difficulty seeing
Ear problems	Infections, running ears, sore ears, hearing problems
Other significant illness	

6-year questionnaire

In the last 12 months how many times has the child attended or been admitted to a HOSPITAL or EMERGENCY CLINIC or been referred to a specialist? *'Number of times' answer option*

6 visits recorded in each measurement wave with the following details

Thinking about the 6 most recent visits, for what illness and how many nights was the visit for?

- Main reason? (see table above for reason options)
- Number of nights in hospital?

APPENDIX 6: NATIONAL MINIMUM DATASET (HOSPITAL INPATIENT EVENTS) VERSION 7.2 TERM DEFINITIONS SOURCE NMDS DATA DICTIONARY AND GLOSSARY (VERSION 1.3 – APRIL, 2008).

Accident Flag

A flag that denotes whether a person is receiving care or treatment as the result of an accident.

Admission

The documentation process, which may include entry to the NHI, by which a person becomes resident in a healthcare facility. For the purposes of the national collections, healthcare users who attend for more than three hours should be admitted.

When calculating the three hours, exclude waiting time in a waiting room, exclude triage and use only the duration of treatment. If part of the treatment is observation, then this time contributes to the 3 hours. 'Treatment' is clinical treatment from a nurse or doctor or other health professional.

Acute admission

An unplanned admission on the day of presentation at the admitting healthcare facility. Admission may have been from the Emergency or Outpatient Departments of the healthcare facility. If the patient is admitted from A&E, then the time of admission should include the time spent in A&E. Treatment carried out in A&E is to be coded on the inpatient event.

Day patient – *referred to as outpatient in this study*

A patient admitted for healthcare with a length of stay less than one day, regardless of intent. See also 'Admission' and 'Intended day case'

Discharge

The process of documentation that changes the status of an admitted healthcare user.

Inpatient

A patient admitted for healthcare, where the intention at admission was that this would not be a day case event. Includes patients who are transferred from another healthcare facility, but not interdepartmental transfers within the same hospital.

Inpatient length of stay

The time in days between admission to hospital 'X' and discharge, death or transfer from hospital 'X', minus leave days from hospital 'X'.

Length of Stay

As above, but equates to midnights spent in hospital

New Zealand Health Information Services (NZHIS)

New Zealand Health Information Service is a group within the Ministry of Health responsible for the collection and dissemination of health-related data.

Outpatient

An outpatient is a patient who receives a pre-admission assessment, or a diagnostic procedure or treatment at a healthcare facility, and who is not admitted, and the specialist's intent is that they will leave that facility within 3 hours from the start of the consultation. When patients receive a general anaesthetic they are deemed not to be outpatients.

Outpatient clinic

A scheduled administrative arrangement enabling outpatients to receive the attention of a healthcare provider. The holding of a clinic provides the opportunity for consultation, investigation and minor treatment, and patients normally attend by prior arrangement. The clinic may be held on or off the hospital site.

Principal diagnosis

The diagnosis established after study to be chiefly responsible for causing the patient's episode of care in hospital (or attendance at the healthcare facility).

The phrase "after study" in the definition means evaluation of findings to establish the condition that was chiefly responsible for the episode of care. Findings evaluated may include information gained from the history of illness, any mental status evaluation, specialist consultations, physical examination, diagnostic tests or procedures, any surgical procedures, and any pathological or radiological examination.

The condition established after study may or may not confirm the admitting diagnosis.

Admission type

A code used to describe the type of admission for a hospital healthcare health event

Includes

- AA = arranged admission
- AC = acute admission
- WN= waiting list/booking list
- ZC = acute, ACC covered (retired 30 June 2004 then identified by use of injury flag)