

## An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative

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**An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.**

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Volume 1 of 1

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I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a higher degree Master of Science by Research, is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

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Student Number \_\_\_\_\_

Date \_\_\_\_\_

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## **List of Abbreviations**

ABA: An Bord Altranais

DNE: Dublin North East

DoH: Department of Health

DoHC: Department of Health and Children

EBM: Evidence Based Medicine

EBP: Evidence Based Practice

HCA: Health Care Assistant

HIQA: Health Information and Quality Authority

HSE: Health Service Executive

IHI: Institute for Healthcare Improvement

IOM: Institute of Medicine

IPFCC: Institute for Patient and Family-Centered Care

MDT: Multi-disciplinary Team

NHS: National Health Service

NMBI: Nursing & Midwifery Board of Ireland

NMPDU: Nursing and Midwifery Practice Development Unit

ONMSD: Office of the Nursing and Midwifery Services Director

PU: Pressure Ulcer

PCA: Primary Care Area

PDSA: Plan-Do-Study-Act

PHN: Public Health Nurse

QD: Qualitative Descriptive

RCPI: Royal College of Physicians in Ireland

SCI: Spinal Cord Injury

WHO: The World Health Organization

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## Summary

**Introduction:** Pressure ulcers (PUs) are common, costly and impact negatively on patients' quality of life. Bearing this in mind, in Ireland, a regional quality improvement collaborative was established within the Health Service Executive entitled 'Pressure Ulcers to Zero', utilizing the SSKIN care bundle in pressure ulcer prevention. As the involvement of patient and family/carer is a central component of health care delivery, this study set out to explore the patient and family/carer experiences and involvement within the collaborative including use of the SSKIN care bundle.

**Methods:** A qualitative descriptive approach was adopted. Since there were 3 main healthcare settings involved in the collaborative (acute /specialist, residential and primary care), one unit from each of these settings was purposively selected to participate. Following ethical approval and written informed consent, data were collected over a 6 week period using semi-structured, one to one interviews with patients, and focus group interviews with family members/carers. Twenty five persons agreed to participate; 16 patients, with varying levels of dependency, and 9 family members/carers .

**Results:** Data were analysed using Colaizzi's Framework, 6 main themes with corresponding subthemes emerged from the analysis: awareness, patient involvement, family/carer involvement, 'prevention is better than cure', 'communication is key' and resources in prevention.

**Discussions:** Both patients and family/carer had limited involvement in PU prevention within the collaborative. Further, a general lack of awareness of the SSKIN care bundle was identified with some confusion surrounding its acronym. Participants expressed the desire to be more involved in PU prevention and the collaborative processes, henceforth, empowering patients and family/carers through education and communication may increase their level of involvement. This has meaning for future collaboratives, where tools, such as acronyms and activities, for example the design and presentation of visual aids pertaining to the collaborative subject, require a patient as well as a professional focus.

**Clinical relevance:** Educating patients and families/carers on PU prevention through utilization of the SSKIN care bundle may facilitate a greater willingness of the patient and family/carer to participate in PU prevention. Also informing and including them in collaborative activities may address quality care issues.

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# **Chapter 1**

## **Introduction and Significance of the Study**

## **1.1 Introduction**

One of the fundamental goals of nursing research is to improve the quality of care provided to patients (Parahoo 1997). Based on this premise, the writer set out to explore the patient and family/carer experiences and their involvement in a regional quality improvement collaborative including use of the SSKIN care bundle (Gibbons *et al.* 2006) in pressure ulcer (PU) prevention. This chapter introduces the background overview of the literature pertaining to the phenomenon under investigation. This will then be followed by a discourse on the significance of the study. Finally a conclusion will be provided.

## **1.2 Background**

Within recent years, there has been a predominantly negative focus on Irish healthcare (HSE 2014). In a response to improve the quality and safety of care being provided, health care leaders and organisations are seeking more effective approaches to change health care practices, with an overall endeavour to improve patient outcomes (HSE 2013b). Traditional healthcare methods have viewed the patient as an outcome of healthcare, but in recent years a shift in paradigms have led to the patient becoming a co-producer of healthcare quality improvement (Andersson & Olderman 2012). Against the backdrop of increased emphasis on quality improvement, healthcare organisations are focusing on involving and engaging patients and families in healthcare planning, service development and research. (Andersson & Oldheden 2012, HSE 2013b, Groene *et al.* 2014).

A contemporary quality improvement approach is based on the idea of collaboratives (Overtveit *et al.* 2002). The quality improvement collaborative is considered to be the health care industry's most innovative and influential response to bridge the gap between quality and safety (Mittman 2004). It is a comprehensive and organised approach to improve healthcare in a chosen area of concern through change processes, using a framework to guide multi-disciplinary collaborative teams (Hulscher *et al.* 2013). The first large scale healthcare quality improvement collaborative to occur in Ireland placed an intentional focus on pressure ulcer (PU) prevention. This collaborative entitled 'Pressure Ulcers to Zero' (HSE 2013a), was supported by the Quality Improvement Division, Health Service Executive (HSE) and the Royal College of Physicians Ireland (RCPI),

through the National Quality Improvement Programme (HSE 2013a). The principal aim of this collaborative was to reduce the incidence of avoidable PUs within the Dublin North East (DNE) region of the Health Service Executive (HSE). In addition it was hoped that the collaborative would increase the capacity and capability of health care professionals to improve the care they deliver (HSE 2013a). It was envisioned that health care teams would partner with patients, families and carer's to achieve these aims (HSE 2013a). At the outset the goal set was to reduce the incidence of avoidable PUs in the participating settings by 50% over six months, with an ultimate goal of reaching of 0%. Within the 6 month time frame, results from the collaborative showed an overall reduction of 73% in PUs in the Dublin North East Region (HSE 2013a).

It is suggested that PUs have been in existence since the dawn of humankind (Moore & Cowman 2012) with the earliest known examples tracing back to Egyptian times (Thompson 1961 cited by Theaker 2003). It is inconceivable that in the present day, PUs are a significant problem across all health care settings (Gorecki *et al.* 2009) despite being largely perceived as preventable (Gallagher *et al.* 2008, Moore *et al.* 2013b, NICE 2014). Consequently, preventing PUs has become an essential aspect of patient safety (Guy 2012). PUs occur when the skin and underlying tissue is damaged as a result of pressure or pressure in combination with shearing forces (NPUAP/EPUAP/PPPIA 2014). They commonly occur over bony prominences where there is insufficient tissue to spread the pressure (Defloor *et al.* 2005, Moore *et al.* 2011). PUs range in size and severity and are categorised according to the level of tissue damage (NPUAP/EPUAP/PPPIA 2014). PUs develop as a result of prolonged unrelieved pressure or mechanical forces (Moore *et al.* 2011). A number of extrinsic factors (for example; pressure, shearing forces) and intrinsic factors (for example; age, mobility, nutrition, incontinence) contribute to PU development (Moore & Price 2004, Benbow 2008). Although PUs can occur across the age spectrum (Edsberg *et al.* 2014), they are most commonly found in the elderly population (Hopkins *et al.* 2006, Benbow 2008). Besides advanced age, patients with an altered state of consciousness or neurological impairment are also at high risk of developing a PU (Bales & Padwojski 2009). Posnett *et al.* (2009) notes that between one in four and one in five acute hospital inpatients have a PU at any time, with most of these



PU identified as being hospital acquired. As such, PUs occur across all health care settings (Fletcher 2012).

In Ireland, prevalence rates of PUs vary from 4% to 37% across a range of settings (Moore *et al.* 2013b). A previous Irish study by Gethin *et al.* (2005), estimated that the cost of successfully treating one grade IV PU was €119,094. Nursing time accounts for 90% of the resource cost for treatment (Dealey *et al.* 2012). PUs impact negatively on patients' quality of life (Gorecki *et al.* 2009, Latimer *et al.* 2014) and are associated with longer hospitalization and increased morbidity and mortality (Redelings *et al.* 2005, Gorecki *et al.* 2010). As a result of the negative health and economic factors that PUs pose, coupled with the knowledge that PUs are preventable, PU prevention is therefore a priority (Johansen *et al.* 2014). Worryingly, despite considerable investment in resources, education and training, the problem of PU development continues to exist, suggesting that there is a need to invest in more effective preventative measures (Moore *et al.* 2013a). This view about the preventability of PUs has underpinned the 'Pressure Ulcers to Zero' (HSE 2013a) collaborative initiative. The process of PU prevention measures involves a myriad of different interventions (Moore *et al.* 2011). These prevention measures are increasingly brought together as a bundle of care known as SSKIN (Gibbons *et al.* 2006). This care bundle consists of a small set of evidence-based practices when performed collectively and consistently improve patient outcomes (Resar *et al.* 2012, Evans *et al.* 2013). The acronym SSKIN stands for Skin inspection, Surface, Keep moving, Incontinence and Nutrition. It is hoped that this care bundle may serve as an important facet in improving PU prevention measures among healthcare providers, thus impacting on the reduction and/or elimination of an adverse outcome for patients.

Within Irish healthcare patient and family-centered care is being adopted into service design and delivery (HSE 2013a). The HSE asserts a commitment to inform and empower all service users to actively participate in their own health and to influence the quality of healthcare in Ireland with the voice of the patient central to all healthcare initiatives (HSE 2013b). Furthermore the National Standards for Better Safer Healthcare, developed by the Health Information and Quality Authority (HIQA), advocate a patient centred approach by focusing on the

outcomes for service users and placing them at the centre of all that the healthcare service does (HIQA 2012). As patients and families/carers are central to the delivery of health care, the 'Pressure Ulcers to Zero' (HSE 2013a) quality improvement collaborative envisioned that a patient and family-centered approach be adopted to guide collaborative processes (HSE 2013a). The patient and family-centered approach requires a partnership between health professionals and the patient and family/carer with shared aspirations for treatment and acknowledgement of peoples life goals (National Asthma Council Australia 2007) as well as understanding people from a holistic perspective (Constand *et al.* 2014). For those patients who are involved in their own care, it is suggested that they are better able to manage their own complex chronic conditions (IHI 2011), there is greater adherence to treatment and medications, with overall better treatment results and greater satisfaction with care received (Larsson *et al.* 2007, Latimer *et al.* 2014). Additionally patients' participation in care has been shown to decrease patients fear and anxiety (Frank *et al.* 2009) with those who have greater participation in their care less likely to experience adverse events (Weingart *et al.* 2011). As PUs are considered as adverse events in healthcare and are considered an indicator of care quality (Moore 2010, Foulkes 2011, HSE 2013a) patient participation could assist to improve standards and impact on quality and safety. Indeed by involving patients and their families/carers in PU prevention interventions utilising the SSKIN care bundle (Gibbons *et al.* 2006) may serve as an effective measure in preventing the development of a PU.

### **1.3 Significance of the study**

The positive results yielded from the regional quality improvement collaborative 'Pressure Ulcers to Zero' (HSE 2013a), which utilized the SSKIN care bundle (Gibbons *et al.* 2006) in PU prevention provided the impetus for a research study to be undertaken. The involvement of patient and family/carer is a central component of health care delivery (HIQA 2012, HSE 2013) and was indeed identified as a central driver in this collaborative approach (HSE 2014a). As such, an information deficit was identified within the literature on the experience of patients and families/carers as key participants in a SSKIN care bundle quality improvement collaborative, subsequently this provided the stimulus for the proposed research study. An initial exploratory qualitative study was warranted. As

recently identified by De Silva (2013), knowing what patients and families or carers think of the care they receive, can be a fundamental component in improving services.

#### **1.4 The Research Question under Investigation**

The research question under investigation in this study is:

*“What is the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative?”*

#### **Aim**

The principal aim of this research study is to explore the patient and family/carer experience of implementing the PU prevention care bundle (known as SSKIN) within a regional quality improvement collaborative entitled ‘ Pressure Ulcers to Zero’ (HSE 2013a).

#### **Objectives**

- To explore the patients and family/carers’ interpretation and understanding of the SSKIN care bundle (Gibbons *et al.* 2006), (e.g. information leaflet, staff communication of the SSKIN care bundle (Gibbons *et al.* 2006) etc.
- To explore the patients and family/carers’ views on the effectiveness of implementing the SSKIN care bundle (Gibbons *et al.* 2006) in preventing PUs.
- To explore the appropriateness and relevance of each of the elements of the SSKIN care bundle (Gibbons *et al.* 2006) for the patients and family/carer providing the care.
- To explore any issues or problems the patient and family/carer may identify relating to their own involvement in the SSKIN care bundle (Gibbons *et al.* 2006).
- To assess the information that patient’s received about the quality improvement collaborative.

It is hoped that by exploring the patients and family/carers experiences, their level of involvement will be identified in PU prevention and use of the SSKIN care

bundle (Gibbons *et al.* 2006). Additionally, it is anticipated that their level of involvement in the quality improvement collaborative process will be revealed. It is proposed that the findings of this study will add to the body of knowledge of health care professionals. By increasing health care professionals understanding of the patient and family experience, it is hoped that this will assist towards developing safer better patient care. Furthermore it is hoped that the results will assist in the spread of the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative to a national level.

### **1.5 Conclusion:**

This chapter has provided a background of the research study under investigation. In addition, the significance of the study was illustrated. The aim of the thesis was achieved through a variety of means undertaken by the writer of which a full discourse will follow. The thesis will be presented in 6 chapters. The introduction has been provided within this chapter. Next, a literature review is provided on the phenomenon under investigation. The following chapter will explore the methodology and research design with an overview on evidence based practice in nursing. Chapter 4 will present the in-depth findings of the patients and family/carer experiences using excerpts from the narratives to support the findings. Following this, a discussion will ensue on the findings presented. Finally, chapter 6 will provide a conclusion and the writer's recommendations for future practices and research.

## **Chapter 2**

### **Literature Review**

## **2.1 Introduction**

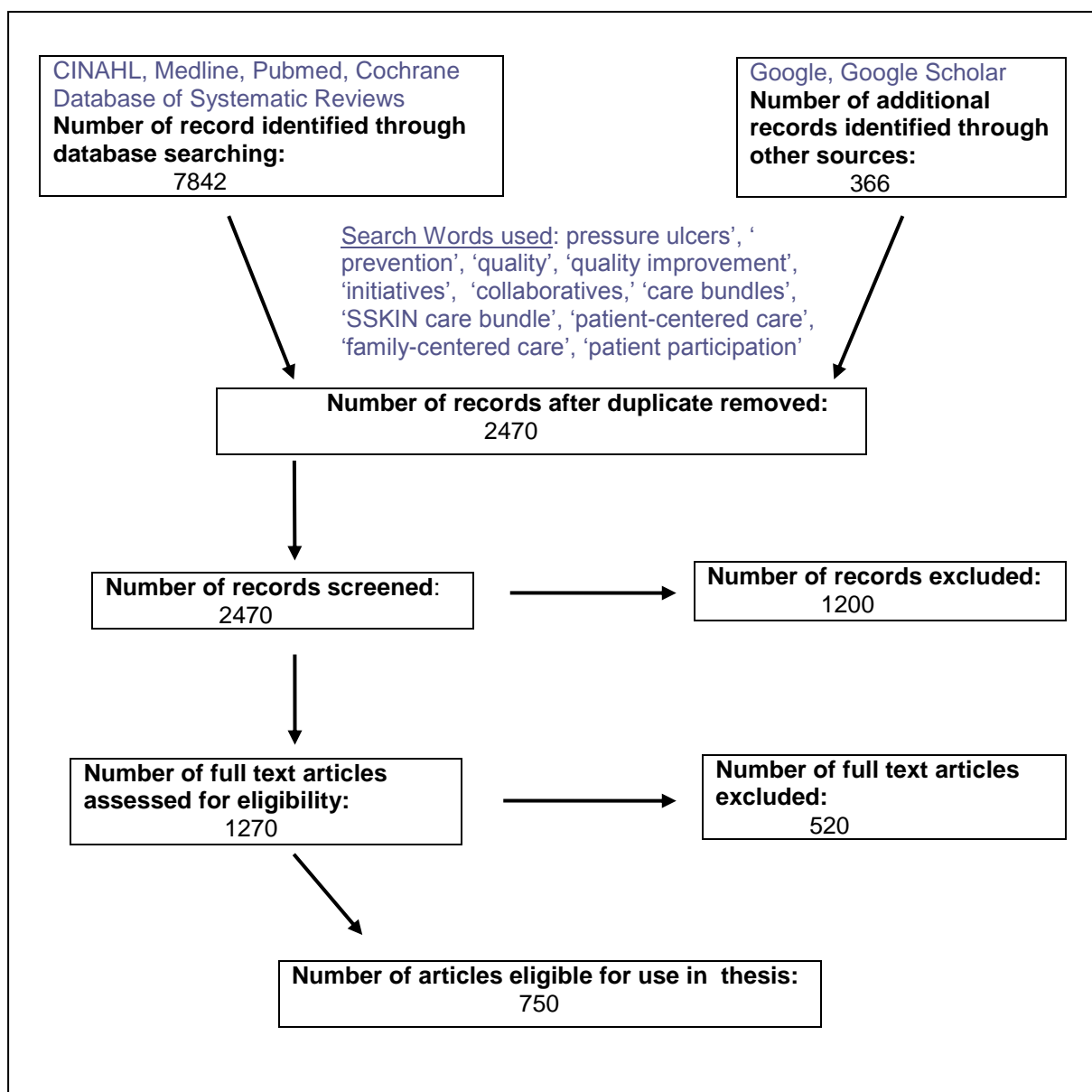
Before embarking on the research process, it is necessary to conduct an integrative review of the literature in order for the researcher to gain a greater understanding of the research topic under investigation (Streubert & Carpenter 2011). A literature review is an amalgamation of the literature that details what is known or studied regarding the research question or purpose (Rebar *et al.* 2011). The chapter will begin with a discourse on the literature surrounding the core aspects pertaining to quality improvement and quality improvement collaboratives in healthcare. Further, a focus will be placed on exploring the patient and family/carer involvement in quality improvement strategies. Next, the chapter will proceed to discuss Ireland's first large scale quality improvement collaborative entitled 'Pressure Ulcers to Zero' (HSE 2013a) with a detailed account on pressure ulcers (PUs) and their effects on both the quality of life of patients and healthcare. This will be followed by a discussion on PU prevention with attention drawn to the use of care bundles and in particular the SSKIN care bundle (Gibbons *et al.* 2006) which has been adopted into practice in an attempt to prevent the occurrence of PUs. As the involvement of patient and family/carer is a central component of health care delivery (HSE 2013b), the concepts pertaining to patient and family centred care will be discussed, with particular attention to patient and family/carer involvement in care practices. Finally, a conclusion will be provided capturing the salient points raised within the preceding sections.

## **2.2 Search Strategy**

A comprehensive search was employed to aid in uncovering theoretical and empirical data pertaining to the research topic. For this purpose literature was searched using specialized databases, which were: Cumulative Index to Nursing and Allied Health Literature (CINHAL), Medline, Pubmed, Cochrane Database of Systematic Reviews (CDSR). Google and Google scholar were searched for additional literature not included in the databases. Additionally, reference lists of the retrieved studies were also manually searched. This was to check for any relevant studies missed during the initial search. The search for relevant studies comprised the key words 'pressure ulcers', 'prevention', 'quality', 'quality improvement', 'initiatives', 'collaboratives,' 'care bundles', 'SSKIN care bundle',

'patient-centered care', 'family-centered care', 'patient participation'. These words were used to search studies' titles and abstracts in order to identify relevant works. Literature was initially searched using the aforementioned key words before conducting the research work. A plethora of literature was unearthed with over 8,000 search results identified originally. Further in-depth analysis of the literature located over 700 search results, all with possible relevance to the research topic. However no published studies were recovered on patients and/or families/carers as key participants in a quality improvement collaborative on PU prevention utilising the SSKIN care bundle (Gibbons *et al.* 2006). See Figure 1: Diagram of search strategy

*Figure 1: Diagram of Search Strategy*



### 2.3 The Need for Quality Improvement in Healthcare

Quality and care are two words that are increasingly interlinked within the literature. Indeed the term quality is being used more frequently to describe the services within healthcare (Murphy 2007). Quality of care has been defined by the Institute of Medicine as;

*‘the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge’* (IOM 1990:4).

A seminal report published in by the Institute of Medicine, ‘To Err is Human: Building a Safer Healthcare System’ (IOM 2000), identified deficiencies in the quality and safety of healthcare in the United States and led towards the worldwide realisation that there was an urgent need to monitor the quality and safety of the care provided and increase efforts at improvement (Mittman 2004). Expanding on this concept, within the report document Crossing the Quality Chasm (IOM 2001), the Institute of Medicine added six fundamental domains to quality, these include: safety, patient-centeredness, effectiveness, efficiency, equity and timeliness. In essence this report has paved the way for intensive efforts internationally to improve health care quality and safety (Mittman 2004).

In recent years there has been a negative and critical focus on Irish healthcare, originating from a number of specific investigations into care quality and patient safety (HSE 2014). Some such investigations include the highly publicised Lourdes Hospital Inquiry (2006) and the most recent HSE report on the Midland Regional Hospital Portlaoise Perinatal Deaths (2014) (HSE2014). These reports have caused a great deal of concern to both the public and the health professionals alike and as such have stimulated an ongoing appraisal of healthcare quality and safety. The World Health Organisation highlights the importance of patient safety, describing it as the prevention of errors and adverse events associated with the provision of healthcare (WHO 2014). Accordingly, health care stakeholders have responded to improve the quality and safety of care being provided, with efforts to identify, understand and correct specific weaknesses in health care delivery (HSE 2013b). Yet Vaismoradi *et al.* (2014)



posit that reducing errors and increasing patient safety through quality improvement, is the shared responsibility of all health care professionals. Similarly, when discussing quality improvement, Batalden & Davidoff (2007) define it as:

*‘the combined and unceasing efforts of everyone – healthcare professionals, patients and their families, researchers, payers, planners and educators – to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning)’.* (Batalden & Davidoff 2007:2).

With the recognition and identification of actual and potential deficits in quality in health care over the last two decades, health care organisations have been prompted to introduce a wide range of initiatives and programmes (Powell *et al.* 2009). Many of these initiatives aimed at improving quality in health care organisations include programmed approaches that build on models and tools first used in industry (Powell *et al.* 2009). Customarily, quality improvement methods utilise a set of techniques and/or approaches that are systematically organized and implemented by an organization to monitor, assess, and improve its quality of health care (HRSA 2014). Take for example Donabedian's (1988) introduction of the triad of structure, process and outcome. In this quality improvement method, activities centre on how to organize structures and processes in order to drive improvements in outcomes over time (Gill & Mountford 2013). For the most part, quality improvement activities are cyclical so that an organization continues to seek higher levels of performance to optimize its care for the patients it serves, all the while striving for continuous improvement (HRSA 2014). Further examples of quality improvement methods include: Total Quality Management (TQM), Continuous Quality Improvement (CQI); Business Process Reengineering (BPR); Lean Thinking and Six Sigma (Powell *et al.* 2009). (See Table 1).

*Table 1: Examples of Quality Improvement Models  
Adapted from Powell et al. (2009)*

Model	Developed	Key Component
Total Quality Management (TQM)/ Continuous Quality Improvement (CQI)	<ul style="list-style-type: none"> <li>▪ Developed in Japan in the 1950's.</li> <li>▪ Use in health care increased in the 1990's.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Emphasis on quality improvement as an ongoing activity</li> <li>▪ Aimed at continuous improvement</li> <li>▪ Focuses on the needs of internal and external customers.</li> <li>▪ Data-driven.</li> <li>▪ Led by managers but carried out by 'empowered' cross-functional teams.</li> <li>▪ Used interchangeably with Continuous Quality Improvement</li> </ul>
Business Process Reengineering	<ul style="list-style-type: none"> <li>▪ Emerged in the US in the 1990s</li> </ul>	<ul style="list-style-type: none"> <li>▪ A radical clean break approach to organisational change.</li> <li>▪ Rarely been implemented to its full extent, whether in health care or in other settings.</li> <li>▪ Emphasis on the importance of examining and redesigning processes.</li> <li>▪ Contributed to a range of more recent redesign initiatives in the UK (and internationally) around patient-centred care (e.g. redesigning care pathways)</li> </ul>
Lean thinking	<ul style="list-style-type: none"> <li>▪ Developed by Toyota in the 1950s</li> </ul>	<ul style="list-style-type: none"> <li>▪ Emphasis on streamlining processes to provide what the internal or external customer wants with minimal wasted time, effort or cost.</li> <li>▪ Use of a range of tools including 5S or CANDO (a series of five steps to enable workforce teams to look at the environment they work in and to start</li> </ul>

		<p>to identify the blocks in current processes) alongside 'value stream mapping' (to remove any unnecessary steps in a process).</p> <ul style="list-style-type: none"> <li>▪ Useful in streamlining processes in support departments rather than mainstream clinical services</li> </ul>
Six Sigma	<ul style="list-style-type: none"> <li>▪ Used in industry since around 1980 and in health care only in the last decade</li> </ul>	<ul style="list-style-type: none"> <li>▪ structured approach (DMAIC – Define Measure Analyse Improve Control)</li> <li>▪ Use of statistical tools (e.g. statistical process control) to identify variations in a process and to distinguish between chance variation and assignable variation.</li> <li>▪ Limited extent in health care, and has some potential for wider application</li> <li>▪ Requires statistical expertise to provide advice and direction on statistical approaches and analysis alongside reliable local data collection</li> </ul>

## 2.4 Quality Improvement Collaboratives

It has been suggested that health care has been slow to implement changes and to make use of methods of quality improvement (Ovrevet *et al.* 2002, Schouten *et al.* 2008). Indeed Bamm & Rosenbaum (2008) postulate that when healthcare experiences a paradigm shift, it often takes some time until the theory gains substantial ground to become generally accepted and implemented. Nevertheless, quality in healthcare cannot be perceived as a static concept as there is a fundamental need for continued improvement (Atkinson *et al.* 2010). Therefore, quality improvement collaboratives are progressively being introduced in many countries in order to stimulate and enhance improvements in patient care and organisational performance (Ovretveit *et al.* 2002, Schouten *et al.* 2008). The quality improvement collaborative is considered to be the health care industry's

most innovative and influential response to bridge the gap between quality and safety (Mittman 2004).

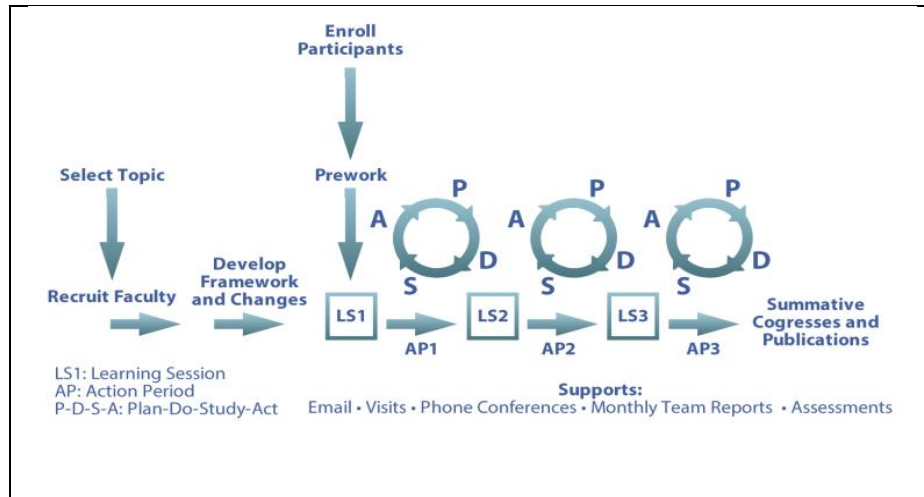
Quality improvement collaboratives have evolved on the foot of the previous continuous quality improvement (CQI) methods devised for use in industry as a way to address manufacturing deficiencies which were then targeted for improvement and reassessment (Nadeem *et al.* 2013). A quality improvement collaborative is a comprehensive and organised approach to improve healthcare (Hulscher *et al.* 2013). The use of this improvement methodology in practice has yielded important results in many organisations and healthcare fields across the United States (IHI 2003). According to reports from the Institute of Healthcare Improvement (IHI), outputs include a reduction in waiting times by 50%, a reduction in ICU costs by 25%, a reduction of the hospitalisation of patients with congested heart failure by 50%, and the reduction of worker absenteeism by 25% (IHI 2003).

The collaborative process brings together groups of practitioners with individual skills, from different healthcare settings, to work in a structured way to guide improvement on one aspect of the quality of their service (Mittman 2004). It involves them joining in a series of meetings or 'learning sessions', which take place over several months, to share and learn from each other about evidenced based practice, quality methods and change ideas, in the chosen area of concern (Overtveit *et al.* 2002, Mittman 2004, Schouten *et al.* 2008). Each learning session is followed by an 'action period' which gives the teams the opportunity to take what they have learned from the learning session, adapt them into their clinical environment and work on changes within their local area (Evans *et al.* 2013). Collaborative learning has accelerated in healthcare and is an interactive process, which recognises the social aspect of learning. This type of learning suggests that teams that work and learn together have a greater potential to improve practice together. (Evans *et al.* 2013).

This type of collaborative learning is based on a framework tool developed in 1995 by the Institute for Healthcare Improvement (IHI 2003). 'The Breakthrough Series Model' (IHI 2003) is frequently referred to within the literature as one of the most

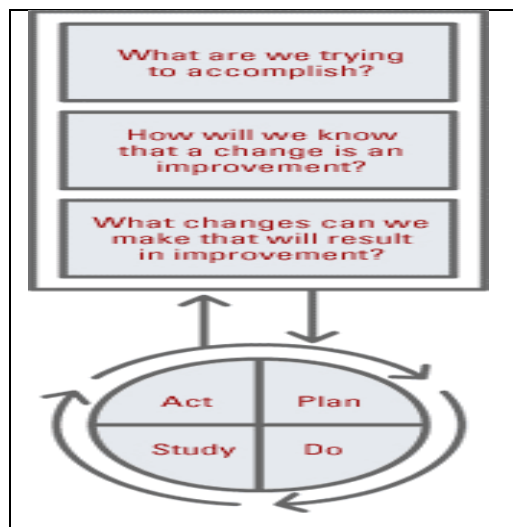
influential frameworks used in quality improvement collaboratives in healthcare (Kilo 1998, Strating & Nieboer 2012) (see figure 1).

Figure 2: *The Breakthrough Series Model, Institute for Healthcare Improvement* (IHI 2003: 5)



Within the Breakthrough Series Model (IHI 2003), lies the Model for Improvement methodology which has been christened the ‘engine for change’ (Kilo 1998). It allows for the measurement of improvements in the process of care and is widely used for rapid cycle improvement. This framework is taught in the collaborative learning process as an aid to structure sustained improvement (Evans *et al.* 2013). The model is grounded on three questions which, when used in conjunction with small and frequent cycles of change Plan-Do-Study-Acts (PDSA) will aid to guide improvement efforts (IHI 2014) (see figure 2). The PDSA cycle enables low-risk tests of change based on the proposals of front line staff and may therefore encourage useful staff engagement in quality improvement (Powell *et al.* 2009).

Figure3: *The Model for Improvement (IHI 2014)*



The World Health Organisation (WHO 2010) endorses the use of collaborative practices to strengthen health systems and improve health outcomes. However, it has been suggested that evidence underlying the effectiveness of quality improvement collaboratives is inconclusive and lacking (Schouten *et al.* 2008, Hulscher *et al.* 2013). From the literature review conducted, there is a dearth of evidence in terms of changes in outcome or practice patterns from the rapid cycle change approach and/or quality improvement collaboratives. This is despite ongoing initiatives of quality improvement collaboratives, the growing number of published papers, validity of the model and the acclamation that many professional appreciate taking part in a collaborative for both professional and organisational development (Ovretveit *et al.* 2002, Schouten *et al.* 2008, Hulscher *et al.* 2013). Yet, in a multiple-case cross-sectional study conducted by Strating & Nieboer (2012), it is argued that most evaluation studies on quality improvement collaboratives are based on one specific topic, thus making it difficult to compare across collaboratives addressing different topics. Furthermore, quality improvement collaboratives differ in improvement methods and function in divergent healthcare sectors and countries, which may in turn influence their effectiveness (Powell *et al.* 2009, Strating *et al.* 2011). Notably, there is a paucity of literature related to the estimated overall costs and investments of collaboratives, however, it has been asserted that they represent considerable investments of time, effort and funding from healthcare organisations (Mittman 2004, Hulscher *et al.* 2013). Nevertheless, organisational support is necessary and

critical to achieve improvement (Strating & Nieboer 2012). From the evidence presented it is apparent that further continuous research on this topic is warranted.

## **2.5 Patient and Family/Carer Involvement in Quality Improvement Strategies**

In an era of improving service provision and quality and safety standards in healthcare, involving patients, listening to and responding to what they have to say is increasingly becoming an integral component in improving quality care (DeSilva 2013). Traditional healthcare methods have viewed the patient as an outcome of healthcare, but in recent years a shift in paradigms have led to the patient becoming a co-producer of healthcare quality improvement (Andersson & Olderman 2012). The World Alliance for Patient Safety (WHO 2005) actively highlights the role that patients and their families could play in the improvement of health care. Congruence exists within the literature on the widespread support for involving and engaging patients and families in healthcare planning and service development and research (Bate & Robbert 2006, Longtin *et al.* 2010, Andersson & Oldheden 2012, Groene *et al.* 2014, Vaismoradi *et al.* 2014). In Ireland, the patient charter *You and Your Health Service* (HSE 2013b) outlines a commitment from the Health Service Executive (HSE) to inform and empower all service users to actively participate in their own health and to influence the quality of healthcare provided, with the voice of the patient central to all healthcare initiatives (HSE 2013b). Additionally the National Standards for Better Safer Healthcare were developed by the Health Information and Quality Authority, as a road map for improving the quality, safety and reliability of healthcare in Ireland. These national standards advocate a patient centred approach by focusing on the outcomes for service users and placing them at the centre of all that the healthcare service does (HIQA 2012)

Weingart *et al.* (2011) proposes that patient and families are an unaccounted source of strength and resilience in health care. It has been suggested that patients are often the first link in reporting adverse events in healthcare (Lyons 2007). Raising awareness about adverse events among patients and families can increase their active participation and engagement in prevention strategies and is therefore considered to be the main motivation for engaging patients in safety initiatives (Vaismoradi *et al.* 2014). Patient participation is founded on the idea that

patients can and should be involved in shared- decision making processes related to how care and services are delivered (Robert *et al.* 2012). Consequently, patient and family involvement in quality improvement can be viewed as part of a wider trend towards a more bottom-up approach of service planning and provision (Wiig *et al.* 2013).

Propounded within the literature is the suggestion that patient and family-centered care can help to shapes policies, programs and facility design within healthcare thus leading to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction (IPFCC 2010). While the rhetoric of patient and family involvement is supported within the literature in health care planning and quality improvement initiatives (Bate & Robbert 2006, Longtin *et al.* 2010, Andersson & Oldheden 2012, Groene *et al.* 2014, Vaismoradi *et al.* 2014), there is little empirical evidence on its effects on the overall results of quality care and safety from the patients and families perspectives. To the writer's knowledge there is no evidence of the experiences of patient and/or family involvement in quality improvement initiatives.

One study found, explored the use of patient involvement and experience in quality improvement in two Norwegian hospitals, comparing perspectives of health care professionals from the macro and micro level (Wiig *et al.* 2013). The extent of involvement of the patients and application of patient experiences in quality improvement work was limited at both hospitals, signalling the need for hospital managers at the macro level to design and implement strategies to assist staff to recognise and value the contribution that patient involvement and experiences can make to improving healthcare quality (Wiig *et al.* 2013). DeSilva (2013) argues that eliciting patient's experiences can be considered as a precursor to quality improvement interventions. Gorecki *et al.* (2009) articulates how failure to utilise patients' perspectives in the development of new measures may pose a threat to the content validity and responsiveness to change, as outcomes relevant to patients may not be included. Indeed the patient experience has become an essential indicator of the performance of healthcare systems worldwide (Robert *et al.* 2012). In order to create a more patient focused health care system, requires



more attention to learning about patients preferences from the patients themselves (Davis *et al.* 2005).

It has been suggested that collecting information from patients can help organisations make better decisions about how to improve services or initiatives (Auras & Geraedts 2010) as well as being linked to better clinical outcomes and reduced costs (DeSilva 2013). An array of methods is available to assess and measure patient experience, satisfaction and expectations. Qualitative methods of data collection have proven to be most efficient and effective to obtain rich information on the patients experiences (Streubert-Speziale & Carpenter 2007). De Silva (2012) suggests that the measurement of patient experience should not be seen as an end in itself but rather as a tool to assess reported experience at a point in time and track these changes. Despite the wealth of evidence available regarding the use of patient experience and patient participation in quality improvement, a consensus exists that more education is required for health care professionals on how to measure patient experience and also how to educate patients on patient participation and its qualities in health care improvement (Robert *et al.* 2012, Wiig *et al.* 2013, Baker 2014). For professionals, understanding and improving patient experience is essential to delivering high quality healthcare (Robert *et al.* 2012). In turn, the patient experience can provide health professionals with invaluable and detailed information, which may lead to better standards of healthcare. Accordingly, these partnerships with patients and families/carers and healthcare professionals can assist in reducing adverse events and improve patient safety and care quality across organisations. However this can only be achieved if patient involvement is valued and supported (Coulter & Ellins 2007). A review of the literature has found a dearth of evidence on patients or families/carers experiences of their involvement in quality improvement collaboratives. It is for these aforementioned reasons that the stimulus for this research study arose. The writer will explore the patient and family/carer experiences of their involvement within a recent quality improvement collaborative in PU prevention.

## **2.6 Pressure Ulcers to Zero: A Quality Improvement Initiative in Ireland**

In Ireland a regional quality improvement collaborative initiative comprising of the Royal College of Physicians of Ireland (RCPI), the National Quality and Patient Safety Directorate and the Dublin North East (DNE) Regional Quality and Patient Safety Directorate of the Health Service Executive (HSE), was established in late 2013 entitled 'Pressure Ulcers to Zero' (HSE 2013a). This is the first large scale healthcare quality improvement collaborative to take place in Ireland (HSE2013a). It was envisaged as a patient centred approach to improve healthcare in relation to PU prevention, using the SSKIN care bundle (Gibbons *et al.* 2006), across a range of healthcare settings (HSE 2013a). The primary aim of the initiative was;

*“To reduce the number of avoidable pressure ulcers across the healthcare system and to increase the capacity and capability of frontline clinical teams to improve the care they deliver” (HSE 2013a).*

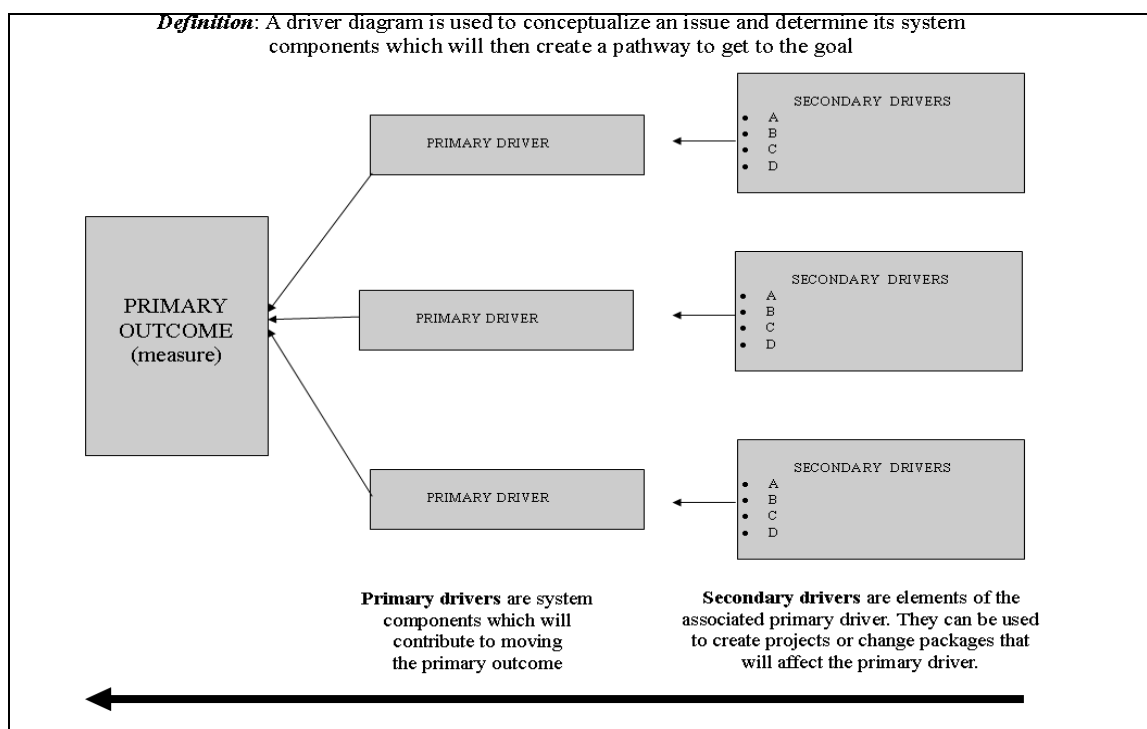
Governance, establishment, site volunteering and pre-work engagement by participants was undertaken in late 2013. The joint programme brought together 21 participating teams in the DNE region from different healthcare settings such as acute/specialist, residential and primary care. Mirroring the previous care bundle methodologies and pathways of predecessors in this field (IHI 2001, NHS UK 2013), each team was composed of multidisciplinary health care professionals including tissue viability nurses, nursing staff, midwives, health care assistants, physiotherapists, occupational therapists and dieticians. Furthermore, the patient and family members/carers were deemed central to drive the focus, with their active participation and engagement inclusive of collaborative activities (HSE 2013a).

The formal timeframe for the 'Pressure Ulcers to Zero' (HSE 2013a) was February 2014-September 2014 with the initial target for the six-month initiative to reduce the number of avoidable PUs by 50% by the end of September. A care bundle known as SSKIN (Gibbons *et al.* 2006) was used as a PU prevention intervention, adopted to target the problem of PUs. Between February- September 2014, the participating MDTs in the 'Pressure Ulcers to Zero' (HSE 2013a) collaborative came together for learning and discussion sessions on how to implement a model

of care to address the problem of PUs within their healthcare setting and indeed improve patient safety and outcomes through change. The aforementioned Model for Improvement (IHI 2003, IHI 2014) was utilised to assist in implementing collaborative processes (HSE 2013a). In addition the Driver Diagram (see figure 3) was chosen as a quality improvement tool used within this collaborative (HSE 2013a). A driver diagram allows you to divide the issue into its various components and helps to set priorities (HSE 2013a).

Virtual shared-learning sessions and networking through WebEx technology occurred in between learning sessions. The data provided by the full team at the end of the appointed 6 month time-frame revealed a successful overall reduction of 73% in PUs in the Dublin North East Region (HSE 2013a). Thereafter teams were encouraged to sustain and spread their improvement with the ultimate goal of reaching an avoidable PU rate of 0% (HSE 2013a). To assist in the sustainability of the collaborative, additional support was provided by Pressure Ulcers to Zero (HSE 2013a) steering group members, through 3 additional follow up sustainability sessions in 2014- 2015.

Figure 4: *The Driver Diagram (IHI 2011)*



## 2.7 Why Pressure Ulcers?

PU are considered as adverse events in healthcare and are therefore an indicator of care quality (DoHC 2008, Moore 2010, HSE 2013a) PUs have been identified as one of the most common types of wounds managed in Ireland (Moore & Cowman 2005). Overall PUs are common, costly and impact negatively on patients' quality of life (Gorecki *et al.* 2009) and are associated with longer hospitalization and increased morbidity and mortality (Redelings *et al.* 2005, Gorecki *et al.* 2010). They pose a significant problem across all health care settings (Goecki *et al.* 2009). Yet PUs are largely perceived as preventable (Gallagher *et al.* 2008, Johansen *et al.* 2014, NICE 2014). It is for these aforementioned reasons that PUs were chosen for a quality improvement collaborative initiative to be conducted in Ireland. A more detailed account of PUs will now ensue.

### 2.7.1 What is a Pressure Ulcer?

In order to illustrate the impact of PUs on the individual, it is important to have a cognisance of the definition of a PU. As such, PUs are also known as pressure sores, bedsores or decubitus ulcers (decubitus, derived from the Latin *decumbere*: to lie down, Bansal *et al.* 2005). A PU is defined by the National Pressure Ulcer Advisory Panel, the European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance as;

*“localised injury to the skin or underlying tissue, or both, usually over a bony prominence, as a result of pressure, or pressure in combination with shear”* (NPUAP/EPUAP/PPPIA 2014:12).

A number of contributing or confounding factors are also associated with PU development, the significance of which are yet to be elucidated (NPUAP/EPUAP/PPPIA 2014). PUs range in severity from non-blanchable erythema of intact skin to full-scale tissue loss and can develop on any part of the body where continuous compressive forces are unrelieved for a sufficient period of time (Bansal *et al.* 2005). However, the most common anatomical sites for PU development are over bony prominences where there is insufficient tissue to

spread the pressure (Defloor *et al.* 2005, Moore *et al.* 2011). Particular vulnerable areas include the occiput, shoulders, elbows, sacrum, hips and heels, (Defloor *et al.* 2005, Moore *et al.* 2011).

Many factors act synergistically to increase the risk of pressure ulceration (Jaul 2010). Indeed, susceptibility to PUs arises from a combination of extrinsic (pressure, shearing forces) and intrinsic factors (e.g. age, mobility, nutrition, incontinence) (Moore & Price 2004, Benbow 2008).

#### **2.7.1.1 Extrinsic & Intrinsic Factors**

It is well acknowledged within the literature that the primary cause of PUs is prolonged, unrelieved pressure (Theaker 2003, Moore *et al.* 2011, NICE 2014). Pressure can be described as a load for example, the patient's body weight, exerted perpendicularly to the tissue, for example the patient's sacrum (Benbow 2008, International Review 2010). The extent of the damage caused by pressure arises as a result of the inverse relationship between the degree of localised pressure and the duration of the pressure (Defloor 1999, Stekelenburg *et al.* 2008). A review of the pathological literature has identified that the mechanisms leading to tissue breakdown were once perceived as largely theoretical (Nixon *et al.* 2005). However emerging evidence suggests that there are four mechanisms within three functional units which lead to PU development (Stekelenburg *et al.* 2008). The mechanisms have been identified as local ischaemia, reperfusion injury, impaired interstitial fluid flow and lymphatic drainage, and sustained deformity of cells. The functional units are the capillaries, the interstitial spaces and the cells (Bouten *et al.* 2003, Moore & Cowman 2012). Despite the vast array of evidence within the literature that the above listed mechanisms play an active role in PU development, the degree of importance and dominance of one factor over another has yet to be determined (Stekelenburg *et al.* 2008, Moore & Cowman 2011).

An additional contributing extrinsic factor in PU development is shearing forces. Shear is a mechanical force exerted parallel to the tissue, whereby a soft tissue stretch deformation occurs when the skin stays in place but the bony structures move across the internal tissue (Bouten *et al.* 2003, Benbow 2008). Although

shear may be classed in a separate entity to pressure, much of the research suggests that one usually accompanies the other as it is difficult to create pressure without shear and vice versa (International Review 2010). Recent research has begun to explore the concept of microclimate in relation to PUs (International Review 2010). Evidence to date suggests that extremes of skin temperature and/or humidity/skin moisture appear to increase the sensitivity of skin to the damaging effects of pressure, shear stresses and friction. However, further research is warranted (International Review 2010).

Coleman *et al.* (2013) argues that a complex interplay of factors increase the probability of PU development. It is well recognised that there are intrinsic contributing factors that predispose an individual to PU development.

Bateman (2012) suggests that intrinsic factors include those that are physically manifest in the individual. Theaker (2003) asserts that intrinsic factors are unique as they increase the individuals response to PU formation. For this reason, there are vast arrays of factors that may fall into this category (Theaker 2003). However amongst the most common include age, malnutrition, dehydration, reduced mobility, sensory impairment, incontinence and chronic illness (NICE 2014). These intrinsic factors contribute to the individual's ability to withstand the exposure to pressure and shearing forces (Moore & Cowman 2012). If combined with the presence of compressive forces such as immobility and inactivity, tissue tolerance to pressure is decreased thus resulting in the potential for PU development. (Bansal *et al.* 2005, Moore & Cowman 2012).

### **2.7.2 Pressure Ulcer Classification System**

Understanding of the definition of a PU in itself is not sufficient to guide everyday practice in the prevention and management of PUs (Riordan & Voegali 2009). Therefore grading systems have been developed to categorise the severity of PUs and these include descriptors ranging from erythema to full-scale tissue loss (Nixon *et al.* 2005). In this regard, the function of a classification system is to standardise the assessment process and provide a universal description of ulcer severity for the purposes of clinical practice, audit and research (Nixon *et al.* 2005, Beeckman *et al.* 2007). Whereas it is argued that within the clinical area there is a need for a robust grading system of PUs in order to indicate PU presence and the

degree of severity of pressure damage, and to enhance the quality of incidence and prevalence studies. Nevertheless, it is postulated that there are disadvantages to using such a grading system, which relate to different users' inaccuracies when grading a PU (Beeckman *et al.* 2007), and to some technical problems when assessing the ulcer. Examples of these problems include the presence of necrotic tissue covering the ulcer and the resulting difficulty in assessing the depth of skin damage (Russell 2002). International evidence based guidelines advocates the utilization of the NPUAP/EPUAP/PPPIA (2014) PU classification system. The level of tissue damage is assessed and classified using a 6 stage classification system (NPUAP/EPUAP/PPPIA 2014) (See Appendix 22).

### **2.7.3 Who is at Risk of a Pressure Ulcer?**

PU's can occur across the age spectrum from infants (Edsberg *et al.* 2014) through to the elderly, where they are more commonly found (Benbow 2008). As such, PU's occur across all health care settings (Fletcher 2012). Besides advanced age, acutely ill hospitalised patients, including those with an altered state of consciousness or neurological impairment are at high risk of developing a PU (Bales & Padwojski 2009). Surgical patients are also particularly prone to pressure injury as a result from prolonged surgical procedures (Schoonhoven *et al.* 2002). Posnett *et al.* (2009) notes that between one in four and one in five acute hospital inpatients have a PU at any time. Also, most of these PU's are identified as being hospital acquired with the majority of PU's occurring relatively early following hospital admission (Posnett *et al.* 2009). Indeed, Padula *et al.* (2008) postulate that PU's can develop in as little as 24 hours yet may take up to five days to present as a visible wound. This has significant implications for the health service, as the length of stay is protracted for those patients who develop a PU (Moore & Cowman 2012).

A recent multidisciplinary conference hosted by NPUAP (2014) presented evidence that 70% of PU's occur in people older than 70 years of age (Edsberg *et al.* 2014), thus concluding that PU development increases proportionally with age. Recent figures from the Central Statistics Office show Ireland's population to be approximately 4.6 million (CSO 2014). Furthermore, demographic forecasts predict an increase in the older population in the future. As a result of the

relationship between age and underlying disease progression, it is reasonable to suggest that one probable outcome of this increasing prevalence of an older population will be a corresponding increase in the prevalence and incidence of PUs (Moore *et al.* 2013b). It is therefore imperative that healthcare institutions place PU prevention at the top of their agenda. Indeed, in the quest to reduce harm to patients' from serious preventable events, national and international institutions have selected PUs as key performance indicators of care quality (Moore 2010, Foulkes 2011, Chaboyer & Gillespie 2014, Johansen *et al.* 2014). Within healthcare there is a drive to improve the services that we, as professionals provide to patients, which in turn makes a difference to the care experienced by patients and families.

#### **2.7.4 Prevalence and Incidence of Pressure Ulcers**

When considering any healthcare problem, it is useful to have a clear impression of the scale of the problem and the burden of care it represents. Dealey (1991) suggests that understanding prevalence rates is a valuable prerequisite in planning PU prevention strategies. However, a study exploring nurses' attitudes, behaviours and perceived barriers towards PU prevention, by Moore & Price (2004) revealed that the staff nurses surveyed were unclear about prevalence rates. As such, PU prevalence and incidence studies serve to give us an idea of the scale of the problem and can be used to evaluate the effectiveness of interventions aimed at prevention and/or management (Clarke *et al.* 2005, Jordan-O'Brien & Cowman 2011). Riordan & Voegeli (2009) portends that the true extent of the problem is difficult to measure due to the lack of standardisation of prevalence and incidence reporting.

PU prevalence is used internationally as an indicator of quality nursing care (Chaboyer & Gillespie 2014). Prevalence refers to the number of people with a PU at a point in time (Moore & Coleman 2011), thus providing an institution with insight as to whether a PU problem exists (Defloor *et al.* 2005). In contrast, incidence refers to the number of persons developing new PUs during a specific time period (Shahin *et al.* 2008). Furthermore, incidence allows for the assessment of adherence and effectiveness of prevention and treatment protocols (Defloor *et al.* 2005). The literature reveals many studies on the prevalence of PUs however,



less is known regarding PU incidence (Keelaghan *et al.* 2008). Fundamentally, incidence has been deemed a more informative way of collecting rich data that could be used to assess the quality of care being delivered, but conversely is less easy to survey and suffers from variance in data collection and measurement tools (Benbow 2009).

Following an integrative review of the literature, it has been observed that prevalence rates vary among different countries and different health care settings. For example, in the United States an overall PU prevalence rate of 11.9% has been reported (Niederhauser *et al.* 2012) while PU prevalence figures collectively across 5 European hospitals were noted at 18.1% (Vanderwee *et al.* 2007a). Further figures illustrate that 20% of patients in acute care settings will develop a PU, with overall prevalence rates varying from 8-23% (Vanderwee *et al.* 2007a). Another study exploring incidence rates concluded that the incidence of PUs for patients under the age of 70 was 8% compared to 19% for those over 70 years (Lindholm *et al.* 2008). From a community perspective, incidence rates range from 4.4%- 6.8% in the UK (McInnes *et al.* 2011).

Previous published Irish studies on PU prevalence identified prevalence rates in the acute setting of 15% (Gethin *et al.* 2005) and 18.5% (Gallagher *et al.* 2008). In the community setting McDermott *et al.* (2009) identified prevalence rates of 4%. A recent international review conducted by Moore *et al.* (2013a), identified 10 Irish studies up to March 2012 inclusive of prevalence (n=6) and/or incidence (n=4) rates. Prevalence varied from 4% to 37% with a mean of 16%. The incidence varied from 8% to 14.4% with a mean of 11%. Rates varied across clinical settings (acute care, long stay care community and spinal cord injury setting). This may be a feature of, not only the care delivered in particular settings, but also of the heterogeneous patient populations and non-standardisation of classification and research design. Regardless of this, the review indicates that PUs are a problem that exists in Irish healthcare.

### **2.7.5 The Financial Impact of Pressure Ulcers**

It is suggested that preventing PUs is less costly than treatment (Akkuzu *et al.* 2009). PUs impose a significant financial burden on health care systems and are

also important predictors of an increased hospital stay for patients (Harrison *et al.* 2013, Thiesan *et al.* 2012). A previous Irish study by Gethin *et al.* (2005), estimated that the cost of successfully treating one grade IV PU was €119,094. On the basis of this figure it was estimated that the total annual cost of managing PUs in Ireland was €250,000,000. In the UK £1.8 - £2.8 billion is estimated to be spent on PU management annually (Posnett & Franks 2008). Nursing time accounts for 90% of the resource cost for treatment (Dealey *et al.* 2012). In addition, patients with PUs not only have longer length of stays in hospital, but are also more likely to be readmitted within 30 days of discharge, and worryingly are more likely to die during their hospital stay (Lyder *et al.* 2012).

In Europe, PU management absorbs approximately 4%-5% of the annual healthcare budget (Moore *et al.* 2014b). Whereas, in the United States of America, PUs cost \$9.1 – \$11.6 billion per year with individual patient costs ranging from \$20,900 to \$151,700 per PU (Agency for Healthcare Research & Quality 2011). In response to the Institute of Medicine's landmark report *To Err is Human: Building a Safer Care System*, the National Quality Forum designated hospital acquired stage III or stage IV PU as never events, i.e. considered avoidable PUs or health care event (IHI 2000). It is because of the aforementioned figures, that in 2008, the Federal Centre for Medicare and Medicaid Services announced it would no longer pay for the ancillary cost of care for NPUAP stage III or stage IV hospital acquired PUs within the US hospitals (Bales & Padwojski 2009). However the financial costs paint only a partial picture of the effects of PUs. The human cost can be particularly devastating (Hopkins *et al.* 2006).

### **2.7.6 Impact on Quality of Life**

To date, empirical studies have shown that PUs represent a major burden to patients and impact negatively on the individuals' quality of life (Hopkins *et al.* 2006, Gorecki *et al.* 2009, Moore *et al.* 2013a). Furthermore, PUs can contribute to an increased risk of morbidity and mortality (Redelings *et al.* 2005, Gorecki *et al.* 2010). In fact, the Institute for Healthcare Improvement (IHI 2011) have estimated that in the U.S. 2.5 million patients develop a PU annually, resulting in 60,000 predicted deaths. For individuals, having a PU can lead to physical, mental, emotional, and social issues on a continuum of severity as identified in a

qualitative study by Spilsbury *et al.* (2007). In this study, pain was reported as a recurrent theme among patients, experienced by 91% of the sample group. These results concur with the previous research findings of Fox (2002), where all study participants described pain as an overwhelming feature of living with a PU. The presence of pain is pertinent to the overall negative impact on patients' quality of life. As such, sleep disturbance, anxiety, reduced mobility and debilitation were the most salient subthemes derived from the endless pain experienced (Fox 2002, Hopkins *et al.* 2006, Spilsbury *et al.* 2007, Gorecki *et al.* 2009).

Malodour and wound exudate were further revealed within the qualitative studies in the literature as distressing complications of living with a PU, thus leading to severe psychological distress and social isolation (Hopkins *et al.* 2006, Spilsbury *et al.* 2007, Gorecki *et al.* 2009). This can lead to reluctance to engage in social interactions. It also affects the sense of taste, thereby reducing appetite at a time when good nutrition is the key for healing and when quality of life is important. This in turn can cause further complications, resulting in weight loss, weakness and lethargy (Price 1996). Intimacy with a loved one is reported by patients as another restriction derived from the presence of a PU (Gorecki *et al.* 2010). Furthermore, PUs are often a complication of an existing disease process. It is therefore reasonable to suggest that the presence of a PU means that that patients not only have to cope with illness, but also the unwanted complication of the PU (Benbow 2009).

## **2.8 Pressure Ulcer Prevention**

Preventing PUs is an essential aspect of patient safety (Guy 2012) and in recent years the prevention of PUs has gained increased emphasis in clinical care practice (Niederhauser *et al.* 2012). As a result evidence-based guidelines for risk assessment and prevention have been made available to clinicians, which act as a valuable resource in facilitating standardisation of care delivery (Evans *et al.* 2013, Moore *et al.* 2013c). However, there is conflicting evidence to suggest that prevention guidelines are not performed consistently (Clarke *et al.* 2005, Jordan-O'Brien & Cowman 2011, Waugh 2014), and studies show that PU prevention is lacking within the clinical practice setting (Wann-Hansson *et al.* 2008, Moore & Cowman 2011). This finding may be a contributing factor to the persistent

prevalence and incidence PU rates within Irish healthcare. Therefore, in the quest to reduce harm to patients from serious preventable events, healthcare institutions have selected PUs as key performance indicators of care quality (Moore 2010, Foulkes 2011, Chaboyer & Gillespie 2014, Johansen *et al.* 2014).

Consistent with existing evidence based clinical practice guidelines, recommendations for PU prevention include (i) risk assessment, (ii) encouraging mobility, repositioning and appropriate support surfaces, (iii) skin care, incorporating the management of wet skin and/or incontinence, and (iv) nutritional assessment and interventions if required (NPUAP/EPUAP/PPPIA 2014). Implicit in this prevention plan, is that upon entry into any episode of care, early risk assessment is the focus that underpins the success of PU prevention with guidelines advocating a comprehensive risk and skin assessment within 8 hours of admission (NPUAP/EPUAP/PPPIA 2014). The Institute for Healthcare Improvement recommend that a risk assessment should be conducted within 4 hours of admission (IHI 2011). In the community, NICE (2014) suggests assessment be carried out on the first point of contact.

Risk assessment scales for PU prevention have been widely used over the last 50 years in different clinical settings (Anthony *et al.* 2008). They are used as a tool for establishing risk according to a series of parameters considered to be risk factors (Pancorbo-Hidalgo *et al.* 2006). Whilst their intent is to enable nurses and staff to constantly and uniformly identify patients who are at risk and to calculate the severity of that risk, their usage does not solely prevent PUs from developing. They serve as a checklist for nurses to identify the most common risk factors that predispose patients to PU development (Moore *et al.* 2011). The synthesis of a validated risk assessment tool with a skin assessment and clinical judgement is endorsed by national and international guidelines (HSE 2009, NPUAP/EPUAP/PPPIA 2014). Following this, preventative interventions may be planned, implemented and evaluated (Moore & Cowman 2014). The widespread adoption of techniques of proven efficiency within PU prevention has the potential to improve healing rates and reduce material costs. However it has been shown that many of the interventions used for PUs are done so incorrectly, may be intrusive and have significant costs (Moore 2014). Consequently, accuracy in

identifying those patients who require prevention strategies is crucial (Moore 2014).

Worryingly, despite considerable investment in resources, education and training, the problem of PU development continues to exist, suggesting that there is a need to invest in more effective preventative measures (Moore *et al.* 2013a). Although prevention measures are available, the process involves a myriad of different interventions (Moore *et al.* 2011). These prevention measures are increasingly brought together as a bundle of care known as SSKIN (Gibbons *et al.* 2006). This innovative blueprint of evidence based best practices developed by the Institute for Healthcare Improvement and Voluntary Hospital Association mirror the core PU preventative strategies outlined by the NPUAP/EPUAP/PIPPA (2014) guidelines.

Successful PU prevention requires a collaborative and multidisciplinary approach (Neiderhausser *et al.* 2012, Moore *et al.* 2014a). Furthermore, interventions directed at preventing PUs also need to be combined with education for patients and their families Akkuzu (2009). However, the responsibility for PU assessment and interventions generally lies with the nurse (Waugh 2014) with commendations calling for the nurse to lead the multidisciplinary team (MDT) (Golden & Miller 2013). As such, nurses must ensure that at risk patients are identified and then provided appropriate prevention interventions based on their individual needs (Institute for Healthcare 2011, NPUAP/EPUAP/PPPIA 2014, NICE 2014).

## **2.9 Multidisciplinary Teams in Pressure Ulcer Prevention**

PU prevention has long been considered a nurse- sensitive quality indicator. In 1860, Florence Nightingale published “Notes on Nursing,” which provided the foundation for many curricula. Her writings heralded the birth of the responsibility of nurses in the prevention of PUs, maintaining that PUs could be prevented by good nursing care. She stated (Nightingale 1980:2): *“If he (a patient) has a bed sore, it is generally the fault not of the disease, but of the nursing”*. Since this statement, PUs have continued to be viewed as very much a nursing problem and of little interest to other health care professionals (Dealey 2012). It is also inferred that such sentiments are gradually disappearing due to the evolving evidence available on the causes of PU development (Dealey 2012). Whilst the nurses’ role

is pivotal in the delivery of PU prevention, the past 30 years have yielded more research in this topic and the findings emanate the importance of a full multidisciplinary team (MDT) approach to PU prevention (Gould *et al.* 2000, Saliba *et al.* 2003, Jua 2010). The validity of this concept is supported in a recent integrative review of the literature by Niederhauser *et al.* (2012) where there is an array of studies describing the use of multidisciplinary programs to prevent the development of a PU. Eliciting a multidisciplinary approach in these programs exhibited improvements in both PU prevalence and incidence rates. Indeed, the collaboration of a MDT is fundamentally important in pressure area care, as no one profession has all the required skills to manage this cohort of patients. (WCON 2009, Moore *et al.* 2014b).

A collaborative team approach to care delivery is recommended by the World Health Organisation (WHO 2010). Furthermore, the Health Service Executive's (HSE), National Best Practice and Evidence Based Guidelines for Wound Management (HSE 2009) advocates the utilisation of a MDT approach to patient care in PU prevention. It must be acknowledged that the success of any MDT requires that all members perform to their full potential and champion collaborative team based care to provide the best possible outcome for the patient (Downie *et al.* 2013, Golden & Miller 2013).

## **2.10 Care Bundles**

In 2001, as part of a joint American healthcare initiative, the Institute of Healthcare Improvement (IHI) and the Voluntary Hospital Association (VHA) developed the 'bundle' concept, with the overall goal of developing processes to the highest level of reliability, resulting in greatly improved patient outcomes (Resar *et al.* 2012). Such bundles are supported by clinical evidence and provide a framework for improving the effectiveness and safety of patient care (McG-Clarkson 2013). Building on this premise, Evans *et al.* (2013) posit that a framework to structure improvement efforts will enable staff to introduce reliable and sustainable changes. The research underlying these bundles emphasises 'reliability' so that every patient receives the care they want and need every time (Whitlock 2013). A bundle of care consists of a small set of evidence-based practices (no more than five), which, when performed collectively and consistently, improve patient outcomes

(Resar *et al.* 2012, Evans *et al.* 2013). Indeed, Crunden *et al.* (2005) posits that when healthcare practice amalgamates research evidence with clinical expertise and patient values, practice improves, resulting in better outcomes for patients, their families and the health care system.

A general consensus of opinion suggests that ineffective care bundles are often contributed to the addition of irrelevant components that are not based on evidence based practice (McG-Clarkson2013). Therefore, it is unanimously recommended that individual components of each care bundle should be well defined and based on strong scientific research evidence (Fulbrook & Mooney 2003, Dawson & Endcott 2011, Evans *et al.* 2103). The bundle is then formulated with the purpose of cementing all components into an individual unit of care that must be implemented for every patient, on every occasion. Each individual component exerts a synergistic effect on the others thus leading to optimal performance and resulting in a greater effect on the positive outcome for patients (Downie *et al.* 2013).

The literature indicates that care bundles have also been shown to encourage clinical practice guideline compliance (McG-Clarkson 2013). Chaboyer & Gillespie (2014) contend that they may also be constructive in situations where there is a deviation of practice and sub-standards of adherence to guidelines are reported. Arguably, Robb (2010) suggests that the bundle approach is more effective than clinical guidelines, as guidelines may be seen as advisory and care bundles are mandatory. There is evidence to suggest that, in Ireland, existing PU prevention guidelines are not integrated consistently (Jordan-O'Brien & Cowman 2011). Others have shown that overall PU prevention is lacking (Moore & Cowman 2011). From an Irish perspective, the bundle approach can therefore act as a driver to improve reliability of the delivery of evidence-based care. The range of interventions identified within a care bundle tackles this problem from a variety of different angles (Dawson & Endacott 2011). Indeed, endorsing MDT engagement, strong communication links, resources and education have proven effective in implementing the bundle approach to quality improvement. (Resar *et al.* 2012, Whitlock 2013). A review of the literature by Dawson & Endacott (2011) identified that a lack of resources will affect nursing staff compliance to care bundles, which

concur with previous studies exploring staff attitudes pertaining to PU prevention (Moore & Price 2004). Therefore, education is deemed an important component for implementing changing practices, but this can be protracted (Gallagher 2007, Whitlock 2013).

Compliance is dependent on all elements of the bundle being achieved every time. If any element of the bundle is not completed, the bundle has not been provided (Resar *et al.* 2012, Evans *et al.* 2013). Moreover, the Institute for Healthcare Improvement (2011) postulate that a complication may arise if one component of the bundle is missed. When auditing compliance with interventions that have been delivered, it is the compliance with the bundle as a whole and not each individual component that is documented as an indicator of successful implementation of evidence-based care (Downie *et al.* 2013). A growing body of evidence within the literature exemplifies a positive relationship between adherence to a care bundle and patient outcomes (Resar *et al.* 2005, Levy *et al.* 2010, Dawson & Endacott 2011). For example, in a well-documented study exploring the use and implementation of care bundles for mechanically ventilated assisted patients across 35 ICU's, results illuminated a significant reduction in ventilated assisted pneumonia among this cohort of patients. Rates of infection were reduced from 5.5 infections to 2.7 infections per 1000 ventilator days (Resar *et al.* 2005). The authors of this study reported that the units with the highest rates of compliance with all aspects of the ventilator care bundle demonstrated the greatest reduction.

The implementation of care bundles into clinical practice has been seen as a fundamental shift in thinking and has received acclamation in other healthcare populations. To date, their use in clinical practice has been widely advocated in (i) mechanically ventilated patients admitted to intensive care units (ii) central venous catheter (iii) peripheral intravenous cannula (iv) sepsis (v) prevention of surgical site infection (vi) urinary catheter care (McG-Clarkson 2013). The successful results of utilising care bundles in the aforementioned healthcare fields, engenders confidence in their potential use as a PU prevention intervention. Care bundles may serve as an important facet in improving PU prevention measures among healthcare providers, thus impacting on the reduction and / or elimination of an adverse outcome for patients. Indeed, in recent years the use of care bundles has



been adopted in the prevention of PUs with significant improvements being reported in overall incidence (Gibbon *et al.* 2006, Institute of Healthcare 2011, Healthcare Improvement Scotland 2011). The SSKIN care bundle (Gibbons *et al.* 2006) has been developed as a comprehensive plan to define best practice to eliminate PUs. Originally introduced to eliminate hospital acquired PUs, their use in clinical practice has since spread across various health care settings. The concept of the care bundle and its introduction to the healthcare system will be explored further in the following sections.

### **2.11 Introducing the SSKIN Care Bundle into Practice**

The acronym SKIN stands for: Surface, Keep moving, Incontinence and Nutrition. The implementation of this program resulted in St. Vincent's Medical Centre being free from stage III and stage IV facility acquired PUs from August 2004 to February 2006 (Gibbons *et al.* 2006). This program has since led to national and international acclamation for its use in PU prevention. In 2010, as part of the '1000 Lives Plus' programme the SKIN care bundle was introduced in Wales. One Health Board tested the SKIN bundle as a pilot site, resulting in a period of over 2 years without development of a PU (Baxter & Downey 2011). Latest figures have reported that the unit has achieved 5 years with only one grade II PU reported (Bartley 2014).

Upon further spread of the program, an additional 'S' denoting 'Skin inspection', was defined and introduced by the National Health Service (NHS) in Scotland. Here it was found that by checking the skin more frequently reddened areas could be identified and treated earlier (Healthcare Improvement Scotland 2011). The SSKIN care bundle (Gibbons *et al.* 2006) has been greatly received throughout the NHS in the UK and has been widely disseminated and developed as a quality improvement initiative. Owing to the profound results authenticated from using the SSKIN care bundle (Gibbons *et al.* 2006) in reducing PUs, this bundle approach has made its introductory debut to Ireland in 2014 as part of an innovative healthcare quality improvement initiative entitled 'Pressure Ulcers to Zero' (HSE 2013a).

## **2.12 SSKIN**

### **2.12.1 (S) Skin Inspection**

Webster *et al.* (2011) suggest that a skin assessment is more useful than a risk assessment tool. Indeed, a thorough skin inspection will highlight early signs of pressure damage (Guy *et al.* 2013). A consensus has emerged in the literature that the presence of grade I PU damage is an important indicator of risk for the development of more severe PU development (Beeckman *et al.* 2007, Moore *et al.* 2011). A systematic review conducted by Coleman *et al.* (2013) noted that there is a strong correlation between a grade I PU and a subsequent grade II or higher graded PU. It therefore reasonable to suggest that the skin should be assessed for early signs of tissue damage, including discoloration and palpable tissue changes including localised temperature, oedema and induration (HSE 2009, Elliot 2010). The presence of skin discoloration necessitates a blanch test to be performed, to assess erythema (Vanderwee *et al.* 2007c). Care must be taken in patients with darkly pigmented skin with research recommending utilisation of the aforementioned alternative indicators to assess for PU damage (Beeckman *et al.* 2007, Guy *et al.* 2013) Reassessment is key and should be completed whenever there is a change in the patients physical or mental state (Whiteing 2009). Further research recommends that skin inspection should be completed as often as possible (Guy *et al.* 2013).

Inspection of the skin should focus on areas most vulnerable in each patient. These are typically over the bony prominences but consideration should also be given to those patients who have any form of hospital equipment in place or attached for example oxygen tubing, intravenous cannulae, tracheostomy tubes, as device related pressure injuries may occur (Whiteing 2009). All findings should be clearly and accurately recorded in the patients' chart, as documentation is an integral component in the assessment of quality of care (Jordan-O'Brien & Cowman 2011).

### **2.12.2 (S) Surface**

The surface on which patients lie or sit can influence their risk of developing a PU. Bony prominences resting against a hard surface result in high pressures at the bone/tissue interface (Guy 2012). Pressure redistribution can be executed by

removal of pressure from the affected part of the body or by reducing pressure by distributing the weight more widely (International Review 2010). This can be achieved through immersion (a measure of how deep an individual sinks into the support surface) and envelopment (the ability of the support surface to mould to fit body contours) (Moore *et al.* 2014a).

Support surfaces play an important role in the prevention and management of PUs and are used with the aim of redistributing pressure, reducing shearing forces and controlling the local microclimate (McInnes *et al.* 2011, Moore *et al.* 2014a).

International guidelines recommend that support surfaces should be chosen on an individual basis depending on the needs and comfort of the patient, the level of mobility and the need for microclimate control (NPUAP/EPUAP/PPPIA 2014). A general consensus within the literature indicates that patients who are at risk of developing a PU should be nursed on high specification foam mattresses rather than standard foam mattresses (Wann-Hansson *et al.* 2008, McInnes *et al.* 2011, Moore *et al.* 2014a). Those who are at a higher risk may require a powered support surface that is able to change its load distribution properties (International Review 2010). A recent Cochrane review by McInnes *et al.* (2011) identified that alternating pressure mattresses are clinically as effective as overlays but were found to be more cost effective and more acceptable to patients.

A correctly fitted chair is invaluable to ensure sufficient pressure redistribution (Elliott 2010). Prolonged chair- sitting serves as another potential stimulus for PU development. It has been recommended that chair sitting should be limited to two hours at any one time (Clark *et al.* 2005) although individual assessment is recommended. Consultation with other MDT members for example, the occupational therapist and the physiotherapist are required to help ensure correct bodily alignment and/or positioning (International review 2010).

When a specialised support surface is in use, it is important that the device is checked regularly to ensure that it is functioning adequately. More importantly, once support surfaces are in place their effectiveness should be assessed. A skin inspection will alert the healthcare professional to the presence or absence of changes to the skin especially over bony prominences (International Review

2010). The patient's pain and comfort should be assessed regularly, as this in turn may contribute to mobility interventions and compliance with equipment. There is supporting evidence to suggest that pressure re-distribution devices used in combination with repositioning techniques can reduce the number of PUs (Vanderwee *et al.* 2007b).

### **2.12.3 (K) Keep moving**

The primary cause of PUs is prolonged unrelieved pressure from lying or sitting on a particular part of the body resulting in oxygen deprivation to the affected area (Defloor *et al.* 2005, Moore *et al.* 2011). Accordingly the level of mobility and range of activity are important factors to consider in assessing an individual's risk of developing a PU (Jaul 2010). Where possible, patients should be encouraged to mobilise and reposition themselves with education provided to the individual and family/ carer on the importance of this. Additionally, clinical guidelines recommend teaching the individuals to do pressure relief lifts or other PU relieving manoeuvres as appropriate (NPUAP/EPUAP/PPPIA 2014, NICE 2014). However the ability for an individual to reposition ones-self is often reduced if they are acutely or chronically ill, have a neurological disorder, are very elderly or are malnourished (Krapfl & Gray 2008, Moore & Cowman 2012). A study conducted by Schoonhoven *et al.* (2002) exploring the incidence of PUs due to surgery showed that 21.2% of the sample size developed a PU in the first two days following surgery. Therefore, early ambulation in post- operative patients is warranted. A timely referral to other MDT members is required to aid in the prevention of a PU.

International best practice advocates repositioning in the prevention of PU development (NPUAP/EPUAP/PPPIA 2014, NICE 2014). Repositioning involves moving the patient into a different position in order to remove or redistribute pressure from a particular part of the body (Krapfl & Gray 2008). Previous studies within the literature have explored the effectiveness of repositioning patients in the prevention of PUs (Defloor *et al.* 2005, Vanderwee *et al.* 2007b). Most recently, Moore *et al.* (2011) conducted a cluster randomised controlled trial across 12 long term care facilities in Ireland, using the 30 degree tilt in repositioning for the prevention of PUs. The study findings revealed a PU incidence of 3% in the experimental group and 11% in the control group. The study concluded that by

repositioning at risk patients every 3 hours at night using the 30 degree tilt, the incidence of PUs was significantly reduced compared to that of standard care i.e. 6 hourly repositioning using the 90 degree lateral rotation. Following on from this study, an economic analysis of repositioning for PU prevention has exhibited the use of repositioning every 3 hours using the 30 degree tilt to be more effective in reducing PUs and is less costly in terms of nurse time (Moore *et al.* 2013a). Use of the 30 degree tilt is advocated by international guidelines (NPUAP/EPUAP/PPPIA 2014).

#### **2.12.4 (I) Incontinence**

Incontinence of urine, faeces or both is a common problem that can affect individuals across all age groups with a higher incidence noted in the elderly (Cooper *et al.* 2008). Moisture as a result of incontinence is implicated in the development of some PUs as a result of the skin being over hydrated (Bateman 2012) making the skin more vulnerable to shearing forces that contribute to pressure damage (Beldon 2008). A systematic review by Coleman *et al.* (2013) identified some evidence that moisture is a factor in PU development with the measures relating to dual incontinence and skin moisture emerging more consistently compared to moisture risk assessment sub-scales, urinary and faecal incontinence. A further systematic review by Beeckman *et al.* (2014) explored the association of incontinence-associated dermatitis, incontinence, and moisture as risk factors for PU development and in 86% of the studies reviewed, a significant association between variables was found. Several factors that are associated with incontinence associated dermatitis can lead the biomechanical pathway to the onset of superficial PUs, these include: (i) inflammation-related skin temperature rise (ii) co-efficients of friction due to wetness e.g. skin wrinkling bed/clothes, (iii) increased shear loads in skin (iv) ageing skin (Gefen 2014). Repeated episodes of incontinence and use of incontinence pads damage the skin, altering its pH thus removing its barrier characteristics (Bardsley 2012). National and international guidelines advocate the need for good skin care to assist in preventing damage to the skin (HSE 2009, NICE 2014, NPUAP/EPUAP/PPPIA 2014). Appropriate cleansing products can be used to maintain the natural skin pH and barrier function with the use of a barrier cream recommended to reduce the risk of skin damage (Bardsley 2012).

### 2.12.5 (N) Nutrition

The literature is unclear about the relationship between malnutrition and PU formation. However, it is postulated that patients suffering from malnutrition are twice as likely to develop a PU as those adequately nourished (Thomas *et al.* 1996). Muscle wasting and tissue loss intensifies the projection of bony prominences which compounds the effects of pressure (Benbow 2008). In essence an improvement in nutritional status along with associated weight gain would increase soft tissue cushioning over bony prominences, helping to distribute pressure on the underlying tissues over a wider area and reducing the risk of blood flow occlusion (Stratton *et al.* 2005). Additionally, the condition of the skin would be improved, thus increasing its resistance to the effects pressure and shearing forces (Stratton *et al.* 2005). It has been suggested that certain nutritional factors appear repeatedly among different populations in studies pertaining to pressure ulceration (Thomas 2001). These include impaired nutritional intake, a reduction in dietary protein intake, the inability to feed oneself and recent weight loss. In a systematic review by Langer *et al.* (2003) evidence was identified indicating that nutritional interventions may reduce the incidence of PUs, however it was deduced that more precise evidence was needed to provide guidance for practice. A study conducted by Iizaka *et al.* (2010) investigating the impact of malnutrition and the role of nutrition on the development and severity of home acquired PUs in elderly people receiving homecare, found nutrition to be a significant risk factor in PU development. Indicative of this, a role for nutrition and indeed a dietitian is warranted in those identified as being malnourished. Congruence exists that nutrition is an important factor in PU prevention and has therefore been incorporated into a variety of guidelines (HSE 2009, NPUAP/EPUAP/PPPIA 2014, NICE 2014).

It was previously mentioned that PUs can develop within the first few hours of hospital admission. Bearing this in mind and coupled with the contributory role that malnutrition can play in PU development, there lies an inherent need for early nutritional screening to allow for early intervention (Johnston 2007). The Malnutrition Universal Screening Tool (BAPEN 2014) is a validated 5 step screening assessment tool to identify adults who are malnourished, at risk of

malnutrition or obese. Recommendations validated within clinical guidelines highlight the importance of completing a comprehensive nutrition assessment of the individual to determine nutritional risk (NPUAP/EPUAP/PPPIA 2014). An assessment should also be conducted to identify the patient's ability to feed oneself.

### **2.13 Patient and Family Centred Approach to Care**

While the SSKIN care bundle (Gibbons *et al.* 2006) approach has been used to great effect in many clinical settings, it is conceived that by involving patients and families in its use, that the potential to prevent PU damage is realised (Vuolo 2014). As patients and families/carers are central to the delivery of health care, the 'Pressure Ulcers to Zero' (HSE 2013a) quality improvement collaborative envisioned that a patient and family-centered approach be adopted to guide collaborative processes (HSE 2013a). To the writer's knowledge, there is no evidence within the literature exploring the patient and family experiences of the SSKIN care bundle in pressure ulcer prevention.

As such, the concept of patient centred care has gained increasing prominence as a key aim of the Irish healthcare system (HSE 2013b, HIQA 2012). As previously mentioned, patient- and family-centered care is an approach within healthcare that shapes policies, programs, organisations, and staff day-to-day interactions all the while leading to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction (IPFCC 2010). Patient centred care is widely favoured as a way to improve patient safety utilising partnerships between patients and healthcare professionals (Weingart *et al.* 2011).

Patient centred care was first unveiled in healthcare as one of the six aims for high quality healthcare in the United States landmark report "*Crossing the Quality Chasm*", from the Institute of Medicine (2001). The report defines patient centred care as:

*"care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions"* (IOM 2001:6).

The IHI (2011) define family as those persons who the patient chooses to call family and not those defined by health care professionals. In family-centered care the unique characteristics of each family and the dignity of each family member are respected. Families are included as partners in care delivery and clinical decision making (Bamm & Rosebaum 2008). From a review of the literature, the writer noted a paucity on information on family-centered care alone. Most definitions and literature are collaborated with those given to patient-centered care (IPFCC 2010, IHI 2011). For this reason the writer will refer to patient-centered care in the reminder of the review.

Davis *et al.* (2005) assert that patient-centered care aims to ensure that all patients have access to the kind of care that works for them. Epstein *et al.* (2010) concurs but adds that patient-centered care should not be acknowledged as surrendering to patients' requests, nor as a throwing of information at people and leaving them to sort out their problems on their own. Indeed, Hobbs (2009) describes it as a complex phenomenon incorporating various interactions between the patient, health professional and the environment with the ultimate goal of alleviating vulnerabilities. Accordingly, the approach requires a partnership between health professionals and the patient with shared aspirations for treatment and acknowledgement of peoples life goals (National Asthma Council Australia 2007) as well as understanding people from a holistic perspective (Constand *et al.* 2014). McCormack & McCance (2006) advocate the inherent good of providing care within the patient-centered philosophy, however they recognize that translating its core concepts into everyday care is challenging. The Picker Institute (1987) unveiled 8 dimensions to patient-centered care, these include;

- Respect for patients' values, preferences and expressed needs
- Coordination and integration of care
- Information, communication and education
- Physical comfort
- Emotional support and alleviation of fear and anxiety,
- Involvement of family and friends
- Transition and continuity
- Access to care



However a recent review by Constand *et al.* (2014) concluded that no unifying patient-centered framework or model was found, but the review identified three consistent core components deemed critical to the process of patient-centered care. These included health promotion, communication and partnership. It is suggested that when drawing on definitions or principles of patient-centered care organisations should design it in accordance to the individual needs and mission of the healthcare institute, as it assists in providing a focus for all healthcare professionals to work together to improve the patient and family experiences (IHI 2011). Yet it is proposed that this in itself may pose as a barrier to its implementation into practice with further barriers identified as changing attitudes among healthcare professionals to adopt a patient focus approach and allocating time to alter this dominant culture (Canadian Foundation for Healthcare Improvement 2014). This signals the implicit need for education among healthcare professionals on the contributions and benefits of adopting this approach into practice. It is expected that by increasing health care professionals understanding of this concept will improve communication with patients and allow clarification of patients concerns and improve their satisfaction with care (Wiig *et al.* 2013). Independent charities are increasingly devising tools and frameworks to assist in providing education to health care professionals on patient and family-centered care. For example in the UK The Kings Fund have recently published its 'Patient and Family Centered Care Toolkit' which provides a simple step by step method to transform patients and families experience of care and assist in creating a culture of patient and family-centered care (The Kings Fund 2014).

## **2.14 Patient Participation in Care Practices**

A growing body of literature suggests that those who are involved in their own care are better able to manage their own complex chronic conditions (IHI 2011). However a paucity of evidence exists on patient and family experiences of their involvement in care practices pertaining to PU prevention. Nevertheless, patient participation in safety initiatives is deemed crucial to the management of overall long term conditions (Anderson & Olheden 2012). It is the expectation that patient participation will give rise to increased motivation to improve their own condition, adherence to treatment and medications, overall better treatment results and greater satisfaction with care received (Larsson *et al.* 2007, Latimer *et al.* 2014). It

has also been shown to decrease patients fear and anxiety (Frank *et al.* 2009). Furthermore, a recent study by Weingart *et al.* (2011) explored hospitalised patients' participation in care and its impact on quality and safety. The results indicated that those with greater participation in their care were less likely to experience adverse events. This has significant meaning for patients and health care professionals alike in relation to PU prevention as PU are considered to be adverse events in health care. As previously highlighted, raising awareness about adverse events among patients and families can increase their active participation and engagement in prevention strategies and is therefore considered to be the main motivation for engaging patients in safety initiatives (Vaismoradi *et al.* 2014). Akkuzu *et al.* (2009) advocate that PU prevention interventions need to include patients and families. However patients' in-depth perceptions on their participation in PU prevention interventions are relatively unknown and so this study hopes to illuminate such findings through their use of the SSKIN care bundle (Gibbons *et al.* 2006).

Previous established practices saw patients expected to be instructed by health care professionals and indeed accept these instructions provided, in order to avoid being unpopular or place themselves at risk of decreased quality of care (Larsson *et al.* 2007). A previous study by Timonen & Sihvonen (2000) found that patients may not be willing to participate in their care due to tiredness and difficulties in composing questions, with limited understanding of terminology used. This is supported in similar findings by Larsson *et al.* (2011) where patients became passive in their care owing to illness, insufficient knowledge and low self-esteem, thus handing over responsibility to nurses. For this reason it seems logical that the health care professional plays a crucial role in supporting, inviting and encouraging patients to participate in their own care, hence promoting active engagement. Partnerships among patients and healthcare professionals are deemed an essential process that underpins participation (Sahlsten *et al.* 2008) and are a key contribution to patient-centered care (Larsson *et al.* 2011). The results of a grounded theory study by Larsson *et al.* (2007) identified that a good nurse-patient relationship and interplay were found to be essential to patients. Further, this provides the basis from which patients can be encouraged to participate in their (Latimer *et al.* 2014). However, Sahlsten *et al.* (2008) argue that the degree to

which patients participate in their own care depends on the nurse. Professional attitudes, lack of insight and knowledge, and the organisation and work environment are perceived to be the main barriers among nurses towards patient participation in care (Larrsson *et al.* 2011).

Consensus exists that shared information and knowledge are deemed a prerequisite for patient engagement and participation (Sahlsten *et al.* 2008, Wigg *et al.* 2013, Constand *et al.* 2014). In turn this promotes positive partnerships (Coulter & Ellins 2007, Latimer *et al.* 2014). Stiggelbout *et al.* (2012) asserts that the principle of shared decision making is an ethical imperative based on the key principles on autonomy, beneficence, and non-maleficence. Shared decision making promotes the right for patient involvement in decisions pertaining to their care (Wiig *et al.* 2013). This process involves the health care professional communicating timely and necessary information such as treatment options and outcome probabilities to patients and families while eliciting and respecting their expectations and preferences for treatment (Coulter & Ellins 2007, Stiggelbout *et al.* 2012). Support for deciding on options should be individualised, using decision aids and evidence based information (Lenz *et al.* 2012).

Patients may be reluctant to participate in care practices if the task is an unfamiliar concept (Davis *et al.* 2011), thereby signalling the need for education. Patient education is endorsed within clinical guidelines pertaining to PU prevention (HSE 2009, NICE 2014, NPUAP/EPUAP/PPPIA 2014). Vuolo (2014) articulates that when educating patients on preventing PUs, patients first need to know what the problem is. As such, clinical guidelines stress the need to inform patients of the causes of PUs, early signs of development, ways to prevent them and the consequences of developing a PU accompanied by a demonstration of preventative techniques (NICE 2014). Evidence is lacking on patient education in PU prevention (Roberts *et al.* 2014). Nevertheless it is suggested that by providing education and informational support it will enhance patients and families health knowledge and recall, especially when it is personalised (Coulter & Ellins 2007). In a study by Akkuzu *et al.* (2009) patients and families found that an educational intervention with both verbal and written teaching, to be a satisfactory way of receiving knowledge on PU prevention. Any health information materials, decision

aids or other technologies have an invaluable role in educating patients and families (Lenz *et al.* 2012), although it is recommended that they are used in conjunction with verbal communicative methods and should not replace the interactions between patients/families and health care professionals (Coulter & Ellins 2007). A systematic review of the literature conducted by Vaismoradi *et al.* (2014) raised an awareness of the importance of education as it results in a two-fold effect for (i) professionals (ii) patients. The review highlighted that patient education improves adherence to management of long term health conditions. However it also provided a wider illumination of the need for further education of professionals regarding patient education and patient care management to promote patient involvement in safety initiatives.

As previously alluded to it was the aim of the Pressure Ulcers to Zero collaborative (HSE 2013a) to adopt a patient and family-centered approach into practice. From the evidence to date, it seems logical that involving patients and their families/carers in PU prevention interventions utilising the SSKIN care bundle (Gibbons *et al.* 2006) may serve as an effective measure in preventing PU development. To the writers knowledge no previous evidence exists within the literature on patients and families/carers experiences of their involvement in a quality improvement collaborative and PU prevention interventions utilising the SSKIN care bundle (Gibbons *et al.* 2006). Therefore the writer will explore this phenomenon as the topic choice for the research study based on the Pressure Ulcers to Zero (HSE 2013a) regional quality improvement collaborative.

## **2.15 Conclusion**

The review of the literature has provided an in-depth discussion of the multifaceted components of the study topic under investigation. This chapter began highlighting the issues surrounding quality and the inherent need for quality improvement practices. Quality improvement collaboratives have been introduced into practice internationally in order to bridge the gap between quality and safety and to stimulate and enhance improvements in patient care and organisational performance. It has been established in this chapter how patients and families/carers are deemed an invaluable resource in quality improvement initiatives with increasing recommendations calling for their participation in

healthcare service design and delivery. However the literature review revealed that there is limited evidence on the patient and family/carer perspective or experience of their involvement in quality improvement collaboratives. Additionally there was a paucity of literature on the effects of their participation in collaborative processes.

The discussion traversed into a discourse on Ireland's first large scale healthcare quality improvement collaborative which entitled Pressure Ulcers to Zero (HSE2013a). This quality improvement collaborative was envisaged as a patient centred approach to improve healthcare in relation to PU prevention, using the SSKIN care bundle (Gibbons *et al.* 2006), across a range of healthcare settings within the Dublin North East Region of the HSE (HSE 2013a). Next, the review provided an exhaustive discussion on PUs, thus generating support for the rationale as to why an intentional focus was placed on PUs for the quality improvement initiative. The rationale stems from the significant problem and burden they pose to individuals and the Irish healthcare. Additionally as PUs are largely perceived as preventable (Gallagher *et al.* 2008, Moore *et al.* 2013b, NICE 2014), this view underpinned the 'Pressure Ulcers to Zero' (HSE 2013a) collaborative initiative. Further discussions established that successful PU prevention requires a collaborative and multidisciplinary approach with PU prevention involving a myriad of different evidence based interventions which have been brought together as the SSKIN care bundle (Gibbons *et al.* 2006). By making the process of preventative care visible through a bundle approach, the reliable delivery of best practice at every opportunity is maximised. Finally, a full discourse occurred on the role of patient and family centered care with a particular focus on patient participation in care practices. Based on the literature presented, it was highlighted how patient and family/carer participation in PU prevention interventions utilising the SSKIN care bundle (Gibbons *et al.* 2006) could serve as a valuable measure in PU prevention. However to the writer's knowledge no previous evidence exists to validate this.

Preliminary results from the 'Pressure Ulcers to Zero' (HSE 2013a) quality improvement initiative are indeed exemplary, making the forecast for the successful implementation of the SSKIN Care Bundle (Gibbons *et al.* 2006) at a national level promising. The literature review highlighted how the patient and

family/carer experience is an important concept in shaping healthcare delivery and quality improvement. Therefore eliciting patients, family members/carer's experiences of their involvement in the Pressure Ulcers to Zero (HSE 2013a) regional quality improvement collaborative and PU prevention through use of the SSKIN care bundle (Gibbons *et al.* 2006), can fundamentally provide us with rich and valuable information to assist in improving standards of care.

# **Chapter 3**

## **Methodology & Research Design**

### **3.1 Introduction**

The research design or methodology is a plan that describes how, when, why and where data will be collected and analysed (Parahoo 1997). The findings of the writer's literature review exhibited a need for research to be undertaken to explore the patient and family/carer involvement in a quality improvement collaborative in PU prevention utilising the SSKIN care bundle (Gibbons *et al.* 2006). This chapter provides a concise outline of the research design employed in this study. A qualitative approach was used to guide the study's plan of action. Making explicit the school of thought that guides a research inquiry assists researchers to conduct a valuable and credible study (Streubert–Speziale & Carpenter 2007). The chapter begins with a discussion on nursing research followed by a discourse on evidence based practice (EBP). It then proceeds to elaborate on the components of research paradigms, in particular focusing on naturalistic inquiry (qualitative research). In addition this chapter outlines the methodology chosen to answer the research question and how elements related to the study design, population, sampling and recruitment techniques were adopted, along with both data collection and data analysis methods. Issues relating to rigour and trustworthiness are explored and ethical issues relevant to this study examined. Finally the chapter ends with a conclusion, drawing together the main points generated within the preceding sections.

### **3.2 Nursing Research**

Caelli *et al.* (2003) illustrate that despite its various forms, the central aim of research is knowledge development. Knowledge is defined as information that is acquired in a number of ways, expected to be an accurate reflection of reality and used to guide a person's actions (Kaplan 1964, cited by Burns & Grove 2007). Burns & Grove (2007) purport that the knowledge required for nursing practice should be both specific and holistic as well as process- orientated and outcomes-focused. Nursing research seeks to gather information in order for us to gain, expand and validate knowledge about health and responses to health outcomes (Rebar *et al.* 2011). Indeed, Parahoo (1997) asserts that the primary goal of nursing research is to improve the quality of care provided to patients.



It is widely accepted that the history of nursing research began with Florence Nightingale and her studies of environmental factors that affected soldiers during the Crimean War in the 19<sup>th</sup> century (Burns & Grove 2007, Rebar *et al.* 2011). Yet, nursing research has been slow to evolve with the most distinguishable changes noted only in recent decades (Moule & Goodman 2014). Deemed as one of the most influential turning points for nursing research, the widely referenced quote from the Briggs Report (1972), stating that '*nurses should become a research-based profession*', has encouraged nurses to engage with and partake in current research (Parahoo 1997, Moulde & Goldman 2014). The literature illustrates that several factors have influenced the growth of nursing research. These include the development and production of nursing journals, the recognition of nursing as a science, an increase in the number of nurses with academic training and essential funding to support research (Burns & Grove 2007, Rebar *et al.* 2011). As a result, nurses have become involved in research relevant to their work, allowing for the focal point of research to evolve, thus formulating the basis for evidence based practice, now deemed the cornerstone of nursing and midwifery practice (Polit & Beck 2014).

### **3.3 Evidence Based Practice in Nursing**

Fundamentally, nurses play a vital role in the delivery of healthcare in Ireland, with the nursing profession formulating the highest proportion (35%) - of hospital staff employed by the Health Service Executive (HSE) (Department of Health 2014). For this reason, it seems logical that nurses should embrace new and innovative techniques to provide effective and efficient care to their patients. Moreover, as nurses are increasingly becoming involved in decision making, it is important for them to utilise the best available evidence to make effective and justifiable decisions (Mantzoukas 2007, Majid *et al.* 2011). Indeed, the Nursing and Midwifery Board of Ireland (NMBI) makes it implicit in the Code of Professional Conduct and Ethics for Registered Nurses and Midwives that they should strive to deliver high quality care that is based on best available evidence (NMBI 2014).

The origin of evidence based practice (EBP) stems from evidence based medicine (EBM) in general healthcare (Sackett *et al.* 1996, Dale 2006). Sackett *et al.* (1996) defines evidence based medicine as;

*“the conscientious explicit and judicious use of current best evidence in making decisions about the care of individual patients.”*

(Sackett *et al.* 1996:71)

Jennings & Loans (2001) purport that the underlying principle of EBM was that of an educational strategy within the medical curriculum. It was devised to promote clinical learning as well as lowering the value of authority opinion and increasing the value of data based studies and research critiques, thereby justifying medical practice. The EBM paradigm was swiftly adopted into other professional healthcare groups, including nursing (Jennings & Loans 2001, Moulde & Goldman 2014). It is unclear from the literature precisely when the switch from EBM to EBP occurred. However it has been implied that the transition has been linked to the need to ensure patient involvement (Jennings & Loans 2001, Dale 2006), with the emergence of EBP holding great promise for producing intended health outcomes (Stevens 2013).

It has been suggested that the major impetus for the increasing prominence in EBP derives from the longstanding concerns of quality and standards in healthcare delivery and concerns over the rising costs of healthcare (Taylor & Allen 2007, Scott & McSharry 2008). Furthermore, the increased availability in new technology has empowered patients and improved their health care knowledge. In turn this has increased demands on the health service to deliver quality outcomes (Melnik and Fineout-Overholt 2005). Thus, EBP is central to nursing practice (Flemming 2007). Implementing EBP can enhance and improve patient care (Eizenberg 2010). Indeed, a meta- analysis conducted by Heater *et al.* (1988) examined the effect of implementing evidence-based interventions on patient care, across eighty- four studies over an eight year period. The meta- analysis measured the effect of research based nursing on four patient outcomes, behavioural, knowledge, physiological, psychological. Concluding results showed

patient outcomes were 28% better compared with those patients who received non-research based care.

Melynk & Fineout- Overholt (2005) suggest that EBP is comprised of 5 stages; formulating a question that will provide an acceptable answer, systematically searching for the most relevant literature, performing a critical appraisal of the evidence, integrating the evidence with clinical practice and patient preferences, and finally evaluating the outcome of the intervention. Both Leufer & Cleary-Holdforth (2009) & Eizenberg (2010) concur and further espouse that by using best evidence in combination with clinical expertise and patient preferences and values, a systematic approach to practice is provided. This in turn enables the nurse to make informed decisions about the most appropriate treatment plans. However, Sackett *et al.* (1996) posit that the critical appraisal of the research is fundamental to identify its strengths and limitations and to ensure that it has sound methodology. This in itself can be a difficult task as over 6000 health related articles are published daily (Levin 2001). Nurses and other health care professionals striving to achieve EBP can become overwhelmed by the sheer volume of published literature available.

A study conducted by Pravikoff *et al.* (2005) examined nurses' perceptions of their access to tools with which to obtain evidence and whether they had the skills to do so. It was demonstrated that although nurses acknowledged that they frequently require information for practice, they consulted colleagues or peers and searched the general Internet. It was found that the nurses involved did not understand the value of research and they did not always possess the knowledge and skills necessary to locate the evidence on which to base their practice. Leufer & Cleary-Holdforth (2009) argue that this is a cause for concern as the implication of EBP not being employed by nurses' results in poor and less than satisfactory outcomes for patients.

As the emphasis in the clinical arena has moved towards EBP, it has become increasingly important that research studies are based on a sound rationale and a clear understanding of the research question (Streubert- Speziale & Rinaldi-Carpenter 2007). The literature review of this study highlighted the involvement of

patients and family/carers as a central component to healthcare delivery. Nevertheless, a gap exists within the literature of their experiences of being involved in quality improvement initiatives. In an attempt to fill this void, the writer chose this subject using a qualitative descriptive approach as it was considered the most appropriate method of research design to explore the patient and family/carer experiences. In order for the writer to gain a cognisance of the qualitative descriptive approach, it was necessary to first explore the background to qualitative approaches as well as the core methodological principles to which qualitative research holds.

### **3.4 Research Paradigms**

The literature presents a general agreement that an understanding of the background from which different methods originate, contributes to better research practice (Patton 2002, Ritchie *et al.* 2014). A research study can be classified according to the paradigm from which it originated (Patton 2002). Guba (1990) defines the term paradigm as a systematic set of beliefs that guides action, resulting in a view of the nature of reality. In essence, paradigms are considered to be a framework or lens through which we view the world (Patton 2002). Guba (1990) connotes that there are several paradigms with which we can use to guide our actions through research. However, Polit & Beck (2014), postulate that nursing research can be achieved within two broad paradigms, positivism and naturalism. The essential difference between these two paradigms lies in their different philosophical assumptions, which in turn guides the data collection and data analysis process (Parahoo 1997).

The positivist paradigm is referred to as a science that aligns the use of instruments or tools to generate numerical data during the research process. It is seen as an objective approach for the researcher in the search for knowledge (Jolley 2013, Polit & Beck 2014). Kelly & Long (2000) contend that positivist research is suitable for experimental studies as the researcher has little interaction with the subjects. Within this context however, the positivist paradigm has been heavily criticised for its study of human beings as though they were objects (Parahoo 1997).

In contrast, the naturalistic paradigm is entrenched in the holistic and individual elements of the phenomena. The overall aim is to capture those elements in their entirety within the context of those who experience it (Creswell 2007). Owing to its philosophical belief that human behaviour can only be understood in real world settings (Patton 2002), and through the meanings that people attach to their lives, the naturalistic approach can therefore be described as interpretative. However an argument prevails within the literature that the naturalistic paradigm encompasses a range of methods that can invariably result in a difference in philosophical assumptions about reality, aims and data collection methods (Sandelowski 1986). Any research findings within this framework are the result of an interaction between the researcher and the participant and the findings are interpretations of the participants' experience (Polit and Beck, 2014). Sandelowski (2000) contends that within the naturalistic inquiry there is an absolute commitment to studying the phenomena in its natural state. By virtue of the discussion presented and for the purposes of this study, which is to explore the patient and family/carer experience of being involved in PU prevention in a quality improvement collaborative, it logically follows that the naturalistic paradigm is most suited to examine the phenomena in question.

### **3.4.1 The Quantitative and Qualitative Debate**

Research paradigms are more commonly referred to as quantitative (positivist) and qualitative (naturalistic) approaches to research inquiry (Rolfe 2006) and are often described in opposition. Yet despite their contrasting features, quantitative and qualitative research approaches complement each other due to their ability to generate different kinds of knowledge that are useful in nursing practice (Burns & Grove 2007). Indeed there exists some similarities between the two paradigms; both require researcher expertise, involve rigor in implementation and generate scientific knowledge for nursing practice (Burns & Grove 2007). Kelly & Long (2000) propose that in choosing the most appropriate approach, the subject or phenomenon under the investigation determines the method of investigation, and this is the fundamental question that must be addressed in the context of the totality of the research endeavour. It must be acknowledged however, some studies may indeed utilise both approaches to explore a phenomenon (Parahoo 1997).

*Table 2: Contrasting characteristics of quantitative and qualitative approaches to research (Parahoo 1997:54)*

<b>Contrasting characteristics of quantitative and qualitative approaches to research (Parahoo 1997: 54)</b>	
<b><u>Quantitative</u></b>	<b><u>Qualitative</u></b>
<ul style="list-style-type: none"> <li>• It is reductionist and/or deterministic</li> </ul>	<ul style="list-style-type: none"> <li>• It is holistic</li> </ul>
<ul style="list-style-type: none"> <li>• Its methods are predetermined, structured standardised and inflexible</li> </ul>	<ul style="list-style-type: none"> <li>• Its methods are semi-and unstructured and flexible</li> </ul>
<ul style="list-style-type: none"> <li>• Its purpose is to measure</li> </ul>	<ul style="list-style-type: none"> <li>• Its purpose is to describe and/or theorise</li> </ul>

In alignment with the tenets of the positivist paradigm, quantitative research is traditionally associated with research in the physical sciences and a number of the social sciences, most notably surveys, experiments and correlational studies of various types (Knapp 1998). Quantitative research uses a formal, objective, systematic process to obtain information about the world, which is presented in numerical data (Burns & Grove 2007) and can be analysed through the use of statistics (Parahoo 1997).

In contrast to the quantitative paradigm, the qualitative paradigm is traditionally associated with research in the humanities and is grounded in the natural social sciences (Knapp 1998, Streubert & Carpenter 2011). Qualitative research is concerned with exploring the phenomena from the interior (Ritchie *et al.* 2014) or indeed as Steurbert & Carepenter (2011; 22) eloquently describe it as '*discovering the emic view*'. Research that utilises the qualitative paradigm attempts to build a complete or holistic picture of the phenomenon of interest (Rebar *et al.* 2011), exploring the social world from the participants' perspective, experiences,

interpretations and meanings that they give and bring to a situation (Astin & Long 2009). Streubert & Carpenter (2011) assert that in the qualitative research paradigm, the main focus is on understanding.

Previous ideologies surrounding qualitative approaches to research depicted that its use was primarily for the discovery of knowledge to be tested and was classed as subsidiary to quantitative research (Carr 1994). A stark contrast now exists as Smith *et al.* (2011) posit that qualitative research can improve quantitative approaches, notably clinical trials, through understanding patient decisions, explicating unusual reactions to treatments and generating new hypotheses. Indeed, Sandelowski (2004) asserts that the proliferation of qualitative health research has resulted in qualitative findings being incorporated into EBP processes. Fundamentally, the qualitative paradigm is most suited to explore a topic of which little is known, gain new insight into phenomena, make sense of intricate situations, compose themes to describe the phenomena and ultimately cultivate a deep understanding of the phenomena (Smith *et al.* 2011). It is for these aforementioned reasons and the paucity of any existing literature, that the qualitative (naturalistic) paradigm was deemed the only way to develop knowledge suited to explore the phenomena in question.

### **3.4.2 Qualitative Approaches to Research**

Qualitative research is not just one approach (Jolley 2013). In fact, it comprises of a variety of approaches and techniques, rendering it difficult to generalise (Parahoo 1997). Arguably Vaismoradi *et al.* (2013) postulate that qualitative approaches generally share a broad philosophy, for example person-centeredness, and are characterised by an open-ended starting point. Be that as it may, with over 40 methods available, it can be challenging for the nurse researcher to choose an appropriate method that meets a study's aim (Smith *et al.* 2011).

Qualitative methods have been described as a diverse set (Elliott & Timulak 2005), encompassing approaches such as;

- Ethnography: a means for studying cultures
- Phenomenology: as a research method it describes the experiences as they are lived, that is, to capture the lived experience of study participants
- Grounded Theory: is an inductive research technique developed for health related topics. The researcher uses this design to a theory around a topic of interest. Its roots are in the data from which it is derived
- Historical Research: examines events of the past (Burns & Grove 2007).

Jolley (2013) argues that although qualitative methods are defined by other authors as '*apparently different approaches*' (Jolley 2013:165), her stance indicates that there is not much difference between them. Indeed, Creswell (2007) posits that qualitative methods encompass a variety of methods that share common attributes. It has been postulated that deliberations about and difficulties in distinguishing between similar qualitative methods, and the over-emersion in the epistemological underpinnings of the chosen method, have resulted in the loss of focus in study aims (Sandelowski 2000) and is undermining the contributions qualitative research could make to evidence- based health care (Sandelowski 2009, Smith *et al.* 2011). Nevertheless, it is important that nurse researchers have a cognisance of the background to qualitative approaches to research as well as the core methodological principles to which qualitative research holds (Denzin & Lincoln 2011). Vaismoradi *et al.* (2013) contend that the philosophical starting points of a study should not be forgotten when seeking differences and similarities in the approaches.

### **3.4.3 Qualitative Descriptive Research**

The research question posed for this study is exploratory and descriptive in nature, seeking to elicit rich data in an attempt to understand in great detail the phenomenon of interest from the participant's perspective. Therefore the writer chose to apply a qualitative descriptive (QD) approach for this study, the rationale for which will ensue. Noteworthy, there is a paucity of literature surrounding the critique of QD approaches to research.



There is no clearly defined approach to QD studies (Milne & Oberle 2005). Qualitative description is frequently criticised for being neither clear nor theory based (Milne & Oberle 2005). However, Neergaard *et al.* (2009) argue that this criticism can only be justified if qualitative description is used for the wrong purposes. In essence, a QD study is suitable when rich, detailed descriptions of phenomena and a focus on the presentation of participant's dialogue with the researcher are desired (Sandelowski 2000). Fundamentally, the QD method poses as a method of choice for a research endeavour that seeks to present the voice of the particular population under study. As suggested by Sandelowski (2000) the researcher remains closer to the words and meanings offered by the participant, and is therefore able to offer a comprehensive summary of the phenomenon in everyday terms. In a discussion on developing and refining interventions with health disparities, Sullivan-Boylai *et al.* (2005) espouse the potential value that QD study results can have directly on health care situations and the ability these results possess to provide clear information about ways to improve care. Indeed, a recent QD study conducted by Carney-Anderson & Fagerlund (2013) exploring the peri-operative experience of patients with Parkinson's disease lends support to the position of Sullivan-Boylai *et al.* (2005). Through the use of semi-structured interviews, a description of patient's experiences using their own words, indicated concerns pertaining to hospital flexibility with medication regimes. In addition it was noted that there was a lack of recognition among hospital staff of patients' expertise in Parkinson's disease. Furthermore it was shown that hospital staff require more education about Parkinson's disease. The outcome of the study resulted in the immediate development of a primer for nurses caring for these hospitalised patients. The results also highlighted the need for clinical care guidelines for hospitalised patients with Parkinson's disease (Carney-Anderson & Fagerlund 2013).

Qualitative description differs from other qualitative traditions in several ways (Sullivan – Boylai *et al.* 2005 & Neerdaard *et al.* 2009). Many of the approaches to qualitative research for example phenomenology, grounded theory and ethnography are based on specific methodological frameworks that have emerged from specific disciplinary traditions (Sandelowski 2000). By comparison QD

studies are inclined to draw from the general tenets of naturalistic inquiry which purports to studying the phenomena in its natural state (Sandelowski 2000). Lambert & Lambert (2012) connote that although phenomenology, grounded theory and ethnography are also classed as descriptive qualitative approaches, they are not exclusive to the descriptive domain as they are inclined to explain phenomena. With the goal of QD studies as that of a rich description of the experience or the event depicted in easily understood language, it therefore differs from that of phenomenology (interpretative meaning of the lived experiences), grounded theory (theory development) and ethnography (thick description) (Sullivan –Bolyai *et al.* 2005). As a result, in the data analysis and data presentation, the researcher stays closer to the data, resulting in a lucid description of participants experiences in a language similar to the participant's own language (Sandelowski 2000, Neergaard *et al.* 2009). However, researchers using a QD approach are free to include what Sandelowski (2000) describes as the tones, hues or textures of other methods. QD studies can borrow from phenomenological, ethnographic and grounded theory methods to provide shades or overtones without creating methodological error. For example, this allows the researcher to apply phenomenological hues that may allow certain words or moments of the experience, while remaining free of phenomenological renderings (Sandelowski 2000).

Another differing pose is that of the interview guide. In QD studies, the interview guide is more structured than in other qualitative methods, yet during the analysis its structure is modified and transformed as themes emerge. The interview guide typically utilises the knowledge of the nurse researcher to focus on areas that are poorly understood in the health care context and/or potentially amenable to intervention (Sullivan-Bolyai *et al.* 2005). As such, it was anticipated by the writer that the QD approach would provide the richest most descriptive data for the research under investigation.

### 3.5 The Research Question

**The research question under exploration in this study is:**

*“What is the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative?”*

#### **Aim**

The principal aim of this research study is to explore the patient and family/carer experience of implementing the PU prevention care bundle (known as SSKIN) within a regional quality improvement collaborative entitled ‘ Pressure Ulcers to Zero’(HSE 2013a).

#### **Objectives**

- To explore the patients and family/carers’ interpretation and understanding of the SSKIN care bundle (Gibbons *et al.* 2006), (e.g. information leaflet, staff communication of the SSKIN care bundle (Gibbons *et al.* 2006) etc.
- To explore the patients and family/carers’ views on the effectiveness of implementing the SSKIN care bundle (Gibbons *et al.* 2006) in preventing PUs.
- To explore the appropriateness and relevance of each of the elements of the SSKIN care bundle (Gibbons *et al.* 2006) for the patients and family/carer providing the care.
- To explore any issues or problems the patient and family/carer may identify relating to their own involvement in the SSKIN care bundle (Gibbons *et al.* 2006) .
- To assess the information that patient’s received about the quality improvement collaborative.

As the involvement of patients/families/carers is a central component of health care delivery (HSE 2013b), it is hoped that by exploring the patients and family/carers experiences, their level of involvement will be identified in PU prevention and use of the SSKIN care bundle (Gibbons *et al.* 2006). Additionally, it is anticipated that their level of involvement in the quality improvement collaborative process will be revealed. It is proposed that the findings of this study

will add to the body of knowledge of health care professionals and assist in the spread of the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative on a national level.

### **3.6 Population**

One of the most important tasks in designing a research project is to decide on the number and characteristics of the participants who will be invited to take part in the study (Parahoo 1997). It must be acknowledged that it is not always possible to include the entire population in a study owing to a number of reasons, predominantly cost and time restraints (Parahoo 1997). A population is defined as the total number of individuals, organisations or events, from which data can potentially be collected (Parahoo 1997). As this study related to the patient and family/carer experiences of the implementation of the SSKIN care bundle (Gibbons *et al.* 2006) within the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative in DNE, the population therefore consisted of all patients and family/carers of patients who were being cared for within the 21 participating sites in the DNE regional quality improvement collaborative. To note, the acute and residential sites involved, each had one or two wards or units participating in the collaborative initiative.

Parahoo (1997) posits that in theory all units (i.e. individuals) of the population could potentially take part in a study, but in practice this may not be feasible for many reasons. It was previously identified in the literature review that PUs can occur across the age spectrum from infants through to the elderly (Edsberg *et al.* 2014). Higginbottom (2004) postulates that it is important to explore different variations of the data in a given case to ensure the full range and extent of the phenomena are represented. There were 21 participating sites (grouped into 3 main categories of settings) involved in the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative; this was the target population (Parahoo, 1997) as in the total population that configures the focus for the study (Procter *et al.* 2010). The writer chose to select one unit from each of these settings (Residential, Acute/Specialist, Primary Care) in order to incorporate the heterogeneous population of patients and families/carers. This subset of the target population is referred to as the study population or sample (Procter *et al.* 2010). Each individual

who participated and provided information was referred to within the research as a study participant. Burns & Grove (2007) espouse the value and success that participants contribute, suggesting that the researcher and participant cooperatively carry out the study.

### **3.6.1 Sampling & Sample Size**

In research the sample selection has a profound effect on the ultimate quality of the research (Coyne 1997). Sampling involves the selection of a portion of the population to represent the population, with the sample derived as a subset of the population units (participants) (Polit & Beck 2014). Within research there are two types of sampling:

- Probability (quantitative): every unit (participant) in the target population has a known chance of being randomly selected from the target population. Types include simple random, stratified random, systematic random and cluster random (Parahoo 1997).
- Non-probability (qualitative): samples are made up of units (participants), using non-random procedures in which every unit does not have a known chance of being involved. Participants are selected on the basis that they will make good informants, who meet the visionary needs of the study. Types include purposive sampling, theoretical sampling, and snowball sampling (Polit & Beck 2014).

In keeping with the aims of QD research, the sample for this study was not selected based on the need to generalise findings but by the desire to achieve rich, valuable, detailed data. Therefore the writer utilised a non-probability strategy of purposive sampling to choose the sample population. Purposive sampling involves the researcher deliberately seeking and choosing individuals as study participants who have specific characteristics or features (Higginbottom 2004). According to Polit & Beck (2014), the purposive sampling strategy involves participants being selected based on their ability to provide the best and appropriate data on the phenomenon under investigation.

Tuckett (2004) suggests that there is no definitive rule for sample size within qualitative research, while Sandelowski (1995a) asserts that numbers play a role

in ensuring that a sample is fully adequate to support the research endeavour. The adequacy of participant numbers involves thoughtful decision-making, as too few participants may risk adequate depth while too many may produce superficial or unwieldy volumes of data (Sandelowski 1995a). A general consensus exists within the literature that the sample size usually relies on small numbers (Parahoo 1997, Patton 2002, Polit & Beck 2014). This is based on the overarching aim to elicit rich and in-depth detail from participants about the particular phenomena in question (Tuckett 2004). Therefore, the sample size is usually determined on informational needs, that is, sampling to the point at which no new information is obtained and redundancy is achieved. This is known as data saturation (Polit & Beck 2014). Sandelowski (1995a) contends that researchers control the sample size numbers by fitting the sampling strategy to the purpose of the chosen research method of the study with appraisal of available resources to conduct the study. It was because of the aforementioned reasons that the writer decided to recruit in each of the sample sites, between;

- 3- 6 patients as participants to conduct one to one interviews (n= 9-18) and
- 4-6 family members/carers to the patients, to participate in a focus group (n=12- 18)

A total yield from 21-36 participants was sought. All of the participants selected for this study were selected because they satisfied a criterion which will be discussed in the following section.

### **3.6.2 Recruitment**

Initial discussions were held between the writer and the gatekeeper in each of the identified sites, in order to seek informal approval from the relevant authorities to access the sites. According to Webster *et al.* (2014) gatekeepers are individuals through whom potential participants are contacted. In healthcare, the gatekeeper possesses a responsibility to protect vulnerable patients from potential harm (Webster *et al.* 2014). Gelling (2010), highlights the importance of negotiating with gatekeepers early in the research planning, as this allows for a rapport to develop. It is also suggested that the gatekeeper can contribute useful suggestions and changes to the planned research in particular prior to the researcher seeking formal ethical approval to conduct the research (Gelling 2010). The gatekeepers in

this study were the Clinical Nurse Managers and Public Health Nurse in the participating sites.

Following ethical approval from the Research Ethics Committees (See Appendix 1 & Appendix 3) and the Primary Care Research Committee (See Appendix 2), the writer sought official approval from the Directors of Nursing (See Appendix 4) and the Clinical Nurse Managers / Public Health Nurse (See Appendix 8) in each site for their permission to access the site and conduct the study. This approval was granted (See Appendix 5, Appendix 6 & Appendix 7). The purposive selection of the participants was performed with the help and consultation of the Clinical Nurse Manager / Public Health Nurse within each participating site.

Participants of the study were selected as;

1. a current participant of the collaborative (current patient or family member/carer) or
2. a previous recent participant (previous recent patient since commencement of the collaborative in February 2014)

Participants for the study were selected using the following inclusion and exclusion criteria:

Inclusion Criteria:

- Patients (or the family member/carer of patients) that are receiving care (or have received care) in a ward / unit participating in the 'Pressure Ulcers to Zero' (HSE 2013a) quality improvement collaborative.
- Patients (or the family member/carer of patients) that are receiving care (or have received care) as per the SSKIN care bundle (Gibbons *et al.* 2006) for the prevention of pressure ulcers.
- Participants included are adults (i.e. over 18 years of age).
- Participants are able to sign an informed consent to be involved in the study, knowing that during the one-to-one or focus group interview they would be expected to express their thoughts and feelings about their experiences.
- Participants are able to speak English.

Exclusion criteria:

- Failure to meet any of the above inclusion criteria.
- Patients that are pregnant

Each participant (patient or family/carer) selected was initially approached by the Clinical Nurse Manager / Public Health Nurse, as gatekeeper, and invited to participate in the study. Permission was sought from the participants for their name to be given to the writer. Once the patient and family member/carer, gave their permission to potentially be recruited for this study, the Clinical Nurse Manager / Public Health Nurse then invited the participant to meet and speak with the writer. The writer approached the participant with the gatekeeper present for the initial visit. This was in an attempt to limit any anxieties that the participants may have had. A thorough verbal explanation was given to each participant regarding the study by the writer and a participant information sheet was provided (See Appendix 9 & Appendix 10 ), which contained all of the writers contact details should the participant have any further questions. Time was spent with the potential participants in an attempt to build a rapport and instil trust. The writer firmly believes that this made a significant contribution to patient and families/carers being more relaxed during data collection. Streubert & Carpenter (2011) highlight the importance of taking the time to build a rapport with those from whom you will be soliciting information. A time frame of 24- 48 hours or a mutually agreed timeframe was allocated in order for the participant to absorb the information and decide whether or not they wished to take part in the study. The writer approached the majority of patients within an agreed time frame of 24-48 hours, while 3 requested alternate times in accordance with their care requirements. The family member/carers necessitated a longer timeframe of up to 4 days, owing to personal commitments. For those participants that volunteered, the writer then invited the participant to a suitable location to proceed with the interview (for patients) or focus group (for family/carers). From a total of 36 preliminary recruitment meetings held, 25 persons agreed to take part in the study.

There was initial concern that there may have been difficulties in recruiting study participants due to the possible discharge or transfer of patients or indeed, in the acute setting, due to the high volume turnover of patients. Therefore a contingency plan was devised which included the potential recruitment of previous recent collaborative participants (i.e. recent inpatient or family member/carer of the patient since commencement of the collaborative in February 2014). This plan



involved each participant being selected through consultation with the relevant Clinical Nurse Manager / Nurse / Public Health Nurse and / or via the HIPE (Hospital Inpatient Enquiry) database for the acute setting. Selected participants were to be contacted via post and invited to take part in the study with. However this contingency plan was not required as the writer was able to recruit a sufficient number of participants in all 3 participating sites.

### **3.7 Data Collection**

At its essence, data collection provides the evidence from which new knowledge can be generated in order to improve and advance nursing practice (Creswell 2007). The most common strategies used for data collection in qualitative studies include interviews, focus groups and observation which are flexible and less structured than that of quantitative research collection tools, which are predetermined, structured and standardised (Parahoo 1997). When choosing the most appropriate strategies for data collection in the study, the researcher must consider the research question, the research approach selected, the sensitivity of the subject matter and available resources (Streubert & Carpenter 2011). In order to gain an understanding of the phenomena as experienced by the participant, the writer chose to collect data for this study in the form of interviews (with patients) and focus group (with family/carer). All data collection occurred over a 6 week period.

The writer wished to ensure that the participants felt comfortable and at ease throughout the study. For this purpose the writer conducted the data collection in a location / venue that was convenient and preferable to the participants. Streubert & Carpenter (2011) assert that the more comfortable the participant is, the more likely they will share important information. Prior to the commencement of any form of data collection, a full explanation of the aims and objectives of the study were given to each participant. Further assurance was given to participants that their confidentiality would be protected and that if they so wished, they could withdraw from the study at any time throughout the study and that this decision would be respected. The writer believed that this aided in assisting the participants to relax as this was imperative to the writer to create a climate of trust. Prior to the commencement of data collection all participants were asked to sign a consent

form indicating their voluntary participation in the study (See Appendix 9 & Appendix 10). As highlighted in the National Consent policy;

*“Consent is the giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention. Consent must be obtained before starting treatment or investigation, or providing personal or social care for a service user or involving a service user in teaching and research”*(HSE 2013c:20).

### **3.7.1 Interviews**

Congruence exists within the literature that the interview is a powerful way to try to understand individuals (Al-Yateem 2012) as it generates deeply contextual accounts of participants experiences (Doody & Noonan 2013). Polit & Beck (2014) define an interview as a method of data collection in which an interviewer asks questions of a respondent either face to face, by telephone or over the internet. Research interviews in particular enable the researcher to collect valid and reliable data to answer a research question (Parahoo, 1997). There are a range of interview formats from which to choose. These include:

- Structured: a rigid format of questions with closed questions. The wording nor the sequence of questions can be altered (Parahoo 1997)
- Unstructured: there is no prior format to the interview and it can be difficult to manage (Parahoo 1997)
- Semi-structured: an open-ended interview in which the researcher is guided by a list of specific topics to cover i.e. an interview guide / schedule (Polit & Beck 2014).

Doody & Noonan (2013) asserts that semi-structured interviews offer flexibility with a chance to explore issues that arise spontaneously and to ask additional questions, thus allowing the researcher the ability to explore new paths that emerge as the interview progresses. With the goal of QD studies as that of a rich description of the experience of the participant depicted in easily understood language (Sandelowski 2000), the writer chose to use semi-structured open ended question scheduling. It allowed the writer the flexibility to explore new avenues that

arose within the one to one interviews thus enhancing the value of the descriptions given. The interview schedule was based on a pre-existing interview schedule (Victor 2013) (See Appendix 15), which was used to explore patients' experiences of repositioning. Permission was sought from the author to adapt the interview schedule and the focus group schedule at the research planning phase. The interview/focus group schedules were expanded to incorporate all practices within the SSKIN care bundle (Gibbons *et al.* 2006) (See Appendix 16 & Appendix 17).

The 16 interviews were carried out as follows: four were conducted in patient participant's home within the PCA. Seven took place in the acute hospital either at the patient's bedside or in the family room, depending on the patients' preference. Finally five were conducted in the residential site in the meeting room or their individual bedrooms, with patient preferences again recognised by the writer as to where they were most comfortable. The interviews were digitally voice recorded, as this was the most efficient way of recording the information. An external microphone was also used to ensure clear and accurate recordings. This allowed the writer to fully engage and commit to the interview. According to Sorrell & Redmond (1995), it is important that while the researcher maintains control of the interview, the researcher must remain flexible to respond to content responses. The writer listened attentively to each participant response, asked follow up questions and probed into some participants' responses for example; 'what do you mean by?', 'can you elaborate on that?'. Whilst the interview progressed the writer took notes in a journal of non-verbal cues and observations from the participants so that the writer could return to these during the analysis and transcription of the data. The length of each interview varied from 13mins44secs to 54mins11secs.

### **3.7.2 Pilot Interview**

According to Van Teijlingen & Hundley (2002) a pilot study can provide the researcher with a clear definition of the focus of the study and can be used as a way to pre-test a particular research instrument or method for example the interview scheduling and technique. Doody & Noonan (2013) recommend that before conducting the research interviews, the researcher should pilot the interview guide. In addition, practising the interview technique can also enhance and develop the researchers self confidence and self awareness (Whitling 2008).

For these aforementioned reasons and also owing to the fact that the writer is a novice in the field of interviewing, the writer conducted a pilot interview. The writer paid attention to ensuring that the participant was at ease throughout the interview process. Additionally the interview schedule was followed with further probing questions asked based on the participants responses. Following the interview the writer transcribed the data collected on the digital voice recorder verbatim listening intently to the voice recording to ensure accuracy and then conducted a brief analysis of the data.

The pilot interview assisted in evaluating the interview schedule, the writer's ability to explore avenues and probing technique based on the participants' responses. It also allowed for evaluation of timing and the equipment used. One area in particular that required attention was the writers' need to execute the probing of participants' responses. The writer realised that it was important to fine tune this skill prior to further interviews being conducted. Overall the pilot interview served as an invaluable learning experience for the writer and aided in relieving any apprehension the writer had in conducting the interviews. Accordingly the pilot interview allowed the writer to proceed with the interviews in confidence. As the data gathered from the pilot interview had such rich valuable detail of the participants' experience, the data was therefore included in the main study.

### **3.7.3 Focus Groups**

Polit & Beck (2014) define a focus group as an interview among a group of participants assembled to answer questions on a given topic. It is an interaction between the researcher and more than one respondent, for the purpose of collecting the research data (Parahoo 1997). It was envisaged by the writer that the group dynamic would encourage participants to share and express their experiences of the phenomenon being researched. The group format has been deemed efficient and can generate a lot of dialogue, explore patient care problems, stimulate new ideas, generate information about services, identify problems and evaluate care (Parahoo 1997, Burns & Grove 2007, Streubert & Carpenter 2011, Polit & Beck 2014). Other advantages to using focus groups include cost effectiveness and time efficiency. However one of the major disadvantages of focus groups is groupthink. This is a process that occurs when

there are stronger members of a group or indeed where segments of the group have major control over the verbalisation of other members within the group (Streubert & Carpenter 2011).

A general consensus exists within the literature that group sizes for a focus group should range from 5-10 participants (Parahoo 1997, Streubert & Carpenter 2011). However, Curtis & Redmond (2007) stipulate that numbers depend on the purpose of the study. Streubert & Carpenter (2011) posit that larger group sizes have been considered to preclude everyone from having a chance to speak. Smaller groups are easier to recruit for and host and are considered to be more comfortable for participants (Polit & Beck 2014). Consequently, for this study, a smaller sample size of 4-6 participants was chosen for each focus group.

The focus groups proved challenging to organise. This was due to the difficulty in co-ordinating different family members/carers time schedules. Prior to commencing the focus group sessions, the writer stressed the importance of confidentiality among the group. In a similar style to that outlined in the interviews, the focus groups were digitally voice recorded thereby allowing the writer to fully engage and commit to the focus group sessions/interview. Within one of the focus group sessions the writer noted that at times one individual spoke across other participants. To ensure that all valuable data was captured from each respondent, the writer took control and referred back to the original speaker to allow them to finish what they wanted to say. Notably, on the day of one of the scheduled focus group sessions only 2 participants attended. However one individual did not wish to participate in a group session and requested that a separate interview be held to which the writer respected. Because of this reason, 2 separate interviews were conducted in this site. All data collected from family members/carer offered invaluable insight into the field of inquiry. The focus groups were carried out as follows: one was conducted in an office of the health centre within the PCA. The other focus group took place in the acute hospital in the family room. Family members who participated in the residential site were interviewed in the meeting room. The length of each session (inclusive of the individual family/carer sessions) varied from 42mins 46secs to 1 hr 17mins 4secs.

### **3.7.4 Reflexivity**

Streubert & Carpenter (2011) contend that before entering the field to conduct interviews, researchers have to be open to their influence on the inquiry. For the novice researcher, it is imperative that they identify and acknowledge their limitations and biases through self-examination (Whitling 2008). According to Polit & Beck (2014) reflexivity in qualitative studies involves critically self-reflecting about one's own biases, preferences and progress in the field of inquiry. Jootun *et al.* (2009) relate reflexivity to the degree of influence that the researcher either intentionally or unintentionally exerts on the findings.

Reflexivity is a continuous process and it should be incorporated into all stages of the research process (Parahoo 1997, Clarke 2006). Finlay & Gough (2003) acknowledge that reflexivity is challenging to do but add that researchers should reflect on their own actions, feelings and conflicts experienced during research. From the outset, the writer made clear her thoughts, ideas, suppositions and biases about the research topic and entered them into a reflective log. Throughout the study the writer constantly scrutinised and wrote down any feelings, preconceptions, conflicts and assumptions she had about the study. This enabled self-examination and self-monitoring to prevent bias and increase objectivity. (Please see Appendix 20)

### **3.8 Data Analysis**

In qualitative research, data analysis is the organisation and interpretation of narrative data for the purpose of discovering important underlying categories, themes and patterns (Polit & Beck 2014). Gathering and analysing data are conducted concurrently in QD research, thus adding to the depth and quality of data analysis (Vaismoradi *et al.* 2013). Hence, when data collection begins so too does data analysis (Parahoo 1997). The process requires a significant degree of dedication and commitment to gain an understanding of what the data conveys (Streubert & Carpenter 2011). According to Streubert & Carpenter (2011), qualitative researchers must connect and engage with the data. They refer to this as dwelling with the data.

### **3.8.1 Transcriptions**

Burns & Grove (2007) recommend researchers to listen to recordings as soon as possible after an interview/focus group and to begin the transcription verbatim immediately. The writer completed this task following each interview/focus group. This allowed the writer to deeply engage with the data. Additionally the writer expanded on notes made in her journal during data collection. All participants' personal data were removed from each transcript to ensure anonymity and confidentiality of their details and that of their family members and the institution. The writer read all transcriptions thoroughly several times while listening to the voice recordings simultaneously to ensure accuracy of the transcriptions. Following the interviews/ focus groups the writer asked all individuals if they wished to review a copy of the transcripts. Only 2 participants requested a copy to which the writer obliged. Subsequently, they contacted the writer to verify and validate the accuracy of the transcripts and no amendments were required. All other participants declined. However the writer left her contact details with the participants should they change their minds.

All information was handled and stored in accordance with the requirements of the Data Protection Act 2003. All of the data obtained was irrevocably anonymised, therefore all identifiable personal details of participants were erased and the transcripts were coded. The patient interviews were coded as Patient A,B,C,D,E,F,G,H,I etc., with the site description included for example; 'Patient A Residential'. The family/carers were coded as Carer 1,2,3,4,5,6 etc., also inclusive of the site description for example; 'Carer 4 Acute'. Within the transcriptions each page and line within the text were numbered. This allowed the writer to extract data, make notes and refer to the narratives in a more timely and efficient manner throughout the data analysis process. All of the raw data was locked away in a secure cabinet accessed only by the writer. The transcribed data was stored on the RCSI V-Drive system and will be stored for a period of 5 years and then destroyed in accordance with RCSI regulations and guidelines.

### **3.8.2 Data Analysis Framework**

Thorne (2000) asserts that data analysis occurs as a specific step in conceptually interpreting the data in its entirety, by using a specific analytic method to transform

the raw data into a new and coherent depiction of the phenomenon under investigation. Owing to the various approaches to qualitative research, there exists many methods of data analysis from which to choose. Sandelowski (1995b) contends that when performing data analysis, the researcher needs to get a sense of the fullness of the data, extract the facts, identify key topics and measure their informational content, using a framework to reduce the data. Vaidmoraidi *et al.* (2013) advocate the use of thematic analysis as a flexible and effective tool in qualitative research to provide a rich, detailed albeit complex account of the data. Thematic analysis involves the exploration and recognition of common themes across a set of interviews (Vaismoraid *et al.* 2013). Due to the aforementioned reasons and given the descriptive nature of the study, the writer decided to conduct a simple thematic analysis using Colaizzi's (1978 cited in Polit & Beck 2014) framework. This method of analysis allowed the writer to conduct a systematic approach in analysing the data, thus ensuring that important data were not omitted. There are seven procedural steps to follow within this framework (Polit & Beck 2014);

- Step 1: Transcribe verbatim, the entire interview from the digital voice recorder and read thoroughly to acquire a feeling of their contents
- Step 2: Extract significant statements and phrases pertaining in particular to the phenomenon under investigation
- Step 3: Create formulated meanings from these statement
- Step 4: Aggregate formulated meanings into theme clusters
- Step 5: Develop an exhaustive description of the phenomenon
- Step 6: Reduce the exhaustive description of the phenomenon to an essential structure
- Step 7: In this final stage the researcher returns the description to its original source for confirmation of validity.

The aforementioned steps of Colaizzi's framework (1978) were employed by the writer and a description of how this was achieved will now ensue.



Step 1: Transcribing the data: In this stage of the analysis process, participants' narratives are transcribed verbatim. Following transcription, the writer immersed herself into the data by reading each of the transcripts countless times to gain a sense of the entire content. Initially the writer read the transcripts while listening to the digital voice recordings to ensure the accuracy of the content. Reading each transcript recurrently allowed the writer to detect any differences or consistencies in participants' experiences. Additionally the writer made notes of any key words that emerged throughout the narratives. For example: prevention, pressure, communication, involvement.

Step2: Extract significant statements or phrases: In this stage of analysis, the writer extracted significant statements and phrases from the narratives of each transcript pertinent to the research inquiry. The writer highlighted any key statements and phrases and made a note in the margins of the transcript. Accordingly these significant statements were assembled and written in separate sheets and coded based on their transcript, page, and line numbers. An example of which is provided in the following table (See Table 2)

*Table3: Examples of Significant Statements*

<b><u>Significant Statements</u></b>	Transcript Code:	Page Number:	Line Number:
<ul style="list-style-type: none"> <li><i>“...you know you need to keep moving because you can get bedsores and we have all heard of bedsores I think over the years. I was never really given any great detail about it at all here though, never”</i></li> </ul>	Pat L Acute	4	107-109
<ul style="list-style-type: none"> <li><i>“ I would be inclined, to be sure, to be sure, that I had a cushion and that I had well if there was anything wrong with my heels again that I'd put them up on a pillow at night”</i></li> </ul>	Pat P PCA	1	17-19

Step 3: Create formulated meanings: In the third stage of the analysis, it is recommended that the researcher attempts to formulate more generalised meanings for each significant statement extracted from participants' narratives (Leigh-Edward & Welch 2011). An example from this study includes;

*"Well they wash me, so if there is anything there, they are going to see it. I mean I won't see it. I'd feel it. But they are the ones that are going to see it"*  
Patient G PCA

General meaning: The participant is dependent on others to assist with hygiene needs and perform a skin inspection.

Step 4: Aggregate formulated meanings: Saunders (2003) maintains that in this section formulated meanings are arranged into clusters of themes. A theme can be defined as the unification of different pieces of data that constitute the findings (Vaismoradi *et al.* 2013). The writer grouped together all the formulated meanings into categories, thus reflecting a unique structure of cluster of themes. The clusters of themes were then coded thus providing clarity to the writer. Six main themes emerged; Awareness, Patient Involvement, Family/Carer Involvement, Prevention is Better Than Cure, 'Communication is Key' and Resources in Prevention. Under each of these themes emerged 15 subthemes. Please refer to Appendix 19 for a visual example on how the themes were constructed from different clusters of themes and formulated meanings.

It is important to acknowledge at this time, that while this study is framed within a naturalistic paradigm, this fact, together with the absence of similar previous research being undertaken in this field, might lead to the conclusion that an inductive approach may be more appropriate to the analysis of results. However, the writer could not conduct a pure inductive analysis approach when analysing the data. This was in part owing to the structure of the interview question scheduling, which incorporated questions surrounding each element of the SSKIN care bundle (Gibbons *et al.* 2006). While the writer believed that this more systematic approach assisted in adding to the richness of the data, the writer also believed this to be a necessity, due to the confusion portrayed by some

participants surrounding the SSKIN acronym. For this reason some of the themes to emerge from the raw data are presented using the frame of the research question and interview question scheduling, thereby adopting a more deductive content analysis approach.

Step 5: Develop an exhaustive description: At this stage of analysis, the writer merged all study themes into an exhaustive description of the participants' experiences and involvement in the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative and in PU prevention utilising the SSKIN care bundle (Gibbons *et al.* 2006) . Furthermore, the writer examined, compared and validated all theme clusters with the original descriptions. It is important that the themes capture what is meaningful and significant in relation to the overall question (Vaismoraidi *et al.* 2013). As such, after merging all of the study's themes, the whole structure of the phenomenon under investigation has been extracted.

Step 6: Reducing the exhaustive description of the phenomenon: In this step, the writer reduced the description of the phenomenon by conducting a rigorous and comprehensive analysis of the exhaustive description. The reduction of the findings resulted in redundant or overestimated descriptions being eradicated from the overall structure. This allowed for what Colaizzi (1978) describes as the identification of the fundamental structure of the phenomenon. Additionally the writer made some amendments to ensure clear relationships existed between clusters of theme and their extracted themes.

Step 7: Returning to participants for validation: Colaizzi (1978) recommends that a follow up appointment be made between the researcher and each participant to validate the essence of the phenomenon. Following the interviews/ focus groups the writer asked all individuals if they wished to review a copy of the transcripts. Only 2 participants requested a copy to which the writer obliged. All other participants declined. Nevertheless the writer left her contact details with these participants should they change their minds but no participant made any further contact with the writer. For those 2 participants who requested a copy, a further scheduled appointment was made with these participants to allow for the writer to present the copy of the transcripts to the participants. All contact details of the

writer were provided. Subsequently, the participants contacted the writer to verify and validate the accuracy of the transcripts. No amendments were required and both participants were happy with the content of the transcripts thereby verifying and endorsing its use in the research study.

### **3.9 Rigor & Trustworthiness**

Much debate and criticism exists within the literature surrounding the issues of reliability and validity within the naturalistic paradigm (Tobin & Begley 2004). Rolfe (2006) argues however that the issues in qualitative research are fundamentally different to those in quantitative research and therefore require different terminology to describe different concepts. It is conceivable, that within qualitative research error can be introduced into a study through the processes of data collection and data analysis (Rebar *et al.* 2011). When considering this, researchers must aim to ensure the rigor of both processes (Rebar *et al.* 2011). Indeed, the responsibility for ensuring rigor lies solely with the researcher (Rolfe 2006). Burns & Grove (2007) describe rigor as striving for excellence in research. As a practical way to ensure the rigor of this study the writer sought peer review of the emerging ideas and themes through discussions with the study supervisors. Sandelowski (1986) contends that a study must be shown to be rigorous, by establishing trustworthiness and by demonstrating a decision trail that can be followed by others. The criterion for establishing rigor and trustworthiness in the qualitative paradigm is outlined by Lincoln & Guba (1985, cited in Polit & Beck 2014). This criterion includes credibility, dependability, confirmability and transferability (Polit & Beck 2014).

#### **3.9.1 Credibility**

Milne & Oberle (2005) postulate that the credibility of any study must be directly related to its purpose. Credibility refers to the confidence that the researcher and user of the research can have in the truth of the data and the interpretation of its findings (Polit & Beck 2014). Within this study the writer maintained an in-depth prolonged engagement with the narratives which enabled the writer to report all participants' perspectives in a clear and concise manner. Member checking as part of the data analysis process is recommended within the literature to promote credibility (Colaizzi 1978, Creswell 2007, Polit & Beck 2014). This involves re-

visiting original participants to check and verify the accuracy of the transcripts. While all participants were offered access and review of the written transcripts, only 2 participants requested copies both of whom verified and validated its use for the research study.

Koch (1994) asserts that credibility is enhanced when researchers describe and interpret their experience as researcher and connotes the importance of self-awareness of the researcher hence there is value in maintaining a research journal throughout the course of the research endeavour (Finlay & Gough 2003). As such, the writer maintained a reflective journal which enabled self-awareness and self-examination. In addition, as a practical way to ensure the rigor of this study the writer sought peer review of the emerging ideas and themes through discussions with the study supervisors.

### **3.9.2 Transferability**

Transferability is the extent to which qualitative findings can be transferred to or relate to other settings or groups (Rebar *et al.* 2011). Sandelowski (1986) argues that the findings need to fit into different contexts outside of the study situation. A concise, rich and vigorous presentation of the findings together with appropriate quotations will enhance transferability (Graneheim & Lundman, 2003). Data retrieved from the one to one interviews and focus groups within this study assisted in this quest. Throughout the research process the writer sought to produce a rich and thorough description of patients and family/carers experiences of their involvement in PU prevention and within the collaborative. The aim was to ensure that the data collected could be used and transferred into other settings and indeed assist in the spread of the Pressure Ulcers to Zero (HSE 2013a) collaborative.

### **3.9.3 Dependability**

Dependability is a criterion met once the researcher has demonstrated the credibility of the findings (Streubert & Carepenter 2011). Dependability represents the consistency and accuracy of the data over time and over conditions (Polit & Beck 2014) and it can be achieved through the process of auditing (Koch 1994). The

writer addressed this criterion by providing the reader with a clear, concise and logical presentation of all stages of the research process undertaken.

### **3.9.4 Confirmability**

Confirmability is established when credibility, transferability and dependability have been achieved (Koch 1994). In confirmability the researcher must establish that all data, findings and interpretations are clearly linked (Topping 2010). This is assured by the use of an audit trail, a recording of activities over time that another individual can follow (Streubert & Carpenter 2011). The writer achieved this by maintaining a record of the raw data, reflective journals, fieldnotes and transcripts, in synergy with Colaizzi's (1978) thematic analysis framework to construct the final report of the findings.

### **3.10 Ethical Considerations**

The personal nature of QD research resulted in several ethical considerations for the writer. Ethical approval was sought and subsequently granted from the relevant Research Ethics Committees (See Appendix 1 & Appendix 3) and the Primary Care Research Committee (See Appendix 2). Additionally all ethical considerations were upheld in accordance with the National Consent Policy (HSE 2013c). The ethical issues that were given due considerations within this study include:

- Beneficence and Non-maleficence: As identified in the Guidance to Nurses and Midwives Regarding Ethical Conduct of Nursing and Midwifery Research (An Bord Altranais 2007- now known as the Nursing and Midwifery Board of Ireland) beneficence means to do good and non-maleficence means to do no harm. Therefore an obligation exists for the researcher to prevent and minimize harm and maximize benefits (Polit & Beck 2014). During the course of the study the writer was aware of the potential that participants may discuss difficult or distressing events. Careful attention was given to all client groups in relation to vulnerability and safety. Therefore, participants were informed that they had the right to withdraw from the study at any time and an appropriate support pathway would be put in place.

During one of the patient interviews, one participant made reference to the fact that they had not be informed by staff about the potential availability of a pressure relieving cushion. The participant appeared quite distressed and expressed their dissatisfaction that they had not been told about them or offered one. They relayed their experiences of high levels of discomfort which they felt had impeded their recovery and as such believed that if they had been given the preference of receiving additional pressure relieving equipment this would have assisted in promoting comfort. As such, they requested that I report their dissatisfaction to the Clinical Nurse Manager of the ward/unit. In accordance with the writers code of professional conduct (NMBI 2014) the writer followed through on their request and reported the participants' level of dissatisfaction.

- Autonomy: Communication and information sharing by the nurse is key to the patients understanding and consenting to any form of nursing care (NMBI 2014). Respect for autonomy was safeguarded by ensuring that all participants received adequate information, both verbal and written, about the study thus allowing them to make an autonomous decision whether or not to take part. For this reason an informed consent was a key ethical consideration in this study. Participants were fully informed of all aspects and proceedings of the research study including the benefits, risks and the right to withdraw from the study at any time.
- Confidentiality: In accordance with An Bord Altranais Guidelines (2007), the researcher is responsible for ensuring the confidentiality and privacy of each research participant and the information obtained from them. Complete anonymity and confidentiality of the participants, ward/unit and the institution were protected at all times. All information was handled and stored in accordance with the requirements of the Data Protection Act 2003. All of the data obtained was irrevocably anonymised, therefore all identifiable personal details of participants were erased. Within the focus groups, the writer identified that there was the potential that personal, detailed information could be disseminated among the group. The importance of confidentiality was highlighted in the participant information

sheet and reiterated to the group by the writer at the beginning of the focus group session. The interview transcripts were stored on a secure encrypted hardware system that was locked a secure cabinet when not in use. All of the hard copies of the data were also stored in the secure cabinet. Both the computer and filing cabinet were kept in the locked office to which only the writer has access. Data will be retained for a period of 5 years to ascertain access to information should future publications or any further research is indicated. Following this time if the data has not been required, it will be destroyed. This information will be stored on a secure password operated server located in the Royal College of Surgeons in Ireland (RCSI) building in Dublin. This is to allow access to information should further research in the area be indicated. There is no intention to re-use the information once the final analysis of the study has occurred. However, should the need arise to re-visit the research information, approval will be sought from the Research Ethics Committee, prior to any further research being conducted. Following the 5 year time frame, all of the information will be destroyed when no longer of use to the study.

### **3.11 Limitations**

This was the first research study performed by the writer and this lack of experience may have contributed to the limitations of the study. One of the main limitations was the overall number of participants interviewed. While valuable information was retrieved from all study participants, the small sample size is perceived as a limitation to the study. The data obtained reflects the perceptions of only a small number of representatives across 3 sites within the regional quality improvement collaborative where overall there were 21 participating sites. Another limitation to this study was the purposive sampling of participants. The gatekeeper was invaluable in identifying suitable participants for this study. However it must be acknowledged that purposive sampling has the capability to eliminate other potential individuals to participate in the research study (Silverman 2000).

In addition, there was some confusion among study participants surrounding the acronym SSKIN. Therefore it was deemed necessary by the writer to adapt the interview question scheduling accordingly in order to discuss and reinforce each



element of SSKIN (Gibbons *et al.* 2006) thus allowing a rich in-depth discourse with participants.

### **3.11.1 Timescale**

As previously stated, the original ethics application submission was August 2014. Ethical approval was not granted officially from the acute site until December 2014. The writer believes that this delay impacted on the study. Contributing factors to the delay included; as there was no research ethics committee sitting in August subsequently a backlog affected the September sitting. The writer's application was not accepted for review until the October 2014 sitting to which the writer had to personally attend. While provisional ethical approval was granted, some amendments were requested which the writer completed and sent to the administrator in a timely manner. Further delays ensued which required the writer's pressing communicative efforts to receive an official response and approval. The approval from this research ethics committee was required before the Primary Care Research committee could consider my proposal and application. However once ethical approval was granted from the acute site, the primary care research committee agreeably expedited my application. As requested, a further application was sent to the academic institutes' Research Ethics Committee, however this did not impact on the study as approval granted by the acute site was recognised by the academic institution. All Directors of Nursing were contacted immediately following ethical approval to allow official access to participating sites, but because of the Christmas holiday season, some responses were not received by the writer until mid January 2015. Recruitment commenced immediately after with data collection beginning in late January. Data collection was completed over a 6 week period. Data analysis was completed by early April 2015, so that the writer could validate her findings, make recommendations for future practice and submit her thesis by July 2015.

### **3.12 Conclusion**

It has been established within in this chapter, that the primary goal of nursing research is to improve the quality of care provided to patients. EBP is central to nursing practice as it can enhance and improve patient care outcomes. This chapter explored the research methodologies and the philosophical underpinnings

of research. It explained why a naturalistic perspective using a QD approach was chosen by the writer to explore the patient and family/carer experience of implementing the SSKIN care bundle (Gibbons *et al.* 2006) within a regional quality improvement collaborative. This chapter also focused on the design and process used by the writer to complete this research. Reflexivity was highlighted as an important aspect in qualitative research studies. Issues relating to rigour and trustworthiness were explored. Finally, the ethical considerations relevant to this study and the procedures undertaken to adhere to their principles were examined. The findings of this study, which explored the patient and family/carer experience of implementing the PU prevention care bundle, known as SSKIN, within a regional quality improvement collaborative, will now be presented in the following chapter.

## **Chapter 4**

### **Presentation of Findings**

## **4.1 Introduction**

This chapter will present the findings of data gathered in relation to the patient and family member/carer experiences of implementing the pressure ulcer (PU) prevention care bundle (known as SSKIN) within a regional quality improvement collaborative. As illustrated in the previous chapter, data was analysed using Collaizi's framework (1978). Data analysis revealed 6 main themes:

1. Awareness
2. Patient Involvement
3. Family/Carer Involvement
4. Prevention is better than cure
5. 'Communication is Key'
6. Responsibility.

Each main theme and its subsequent sub-themes are described in detail below with excerpts from participants' narratives provided, to illustrate key points.

## **4.2 Demographics**

Following exhaustive attempts to recruit study participants, in total 25 participants across the three settings agreed to take part in the study. All participants met the study inclusion criteria, as identified through consultation with the gatekeepers in each site. For the one to one patient interviews 16 participants (9 female and 7 male) agreed to partake with a mix of genders across the 3 settings. Patients ranged in age from 32 to 85 years with varying levels of dependency. The writer wishes to acknowledge, that within the residential site, the individuals who reside there are referred to as 'residents'. However for the purposes of the presentation of this research study, they will be referred to under the title of 'patients'. In the residential site, all patients (n=5) were wheelchair bound with paralysis present in most patients in the form of quadriplegia, paraplegia and hemi-plegia to an affected side. These patients had lived in the residential site for a number of years. Within the acute site all patients (n=7) who were taking part in the study were surgical, post-operative inpatients. Their length of time in hospital during their current inpatient stay ranged from 4 days to 3months. However, one patient was a readmission having had a previous length of stay greater than one year. Patients within the Primary Care Area (PCA) (n=4) had a varying level of dependency, 3 of

whom relied on carers, live-in and/or drop-in, to perform activities. The fourth participant lived with their spouse.

The focus groups were predominantly composed of family members, with only one privately employed carer in attendance. It is important to point out that none of this group, called carers for the purposes of the study, were related to any of the patient participants of this study. A total of 9 participants (majority female) agreed to take part in this segment of the study. In the PCA, 4 live-in or drop-in carers participated. The acute site as identified in the previous chapter, proved to be the most difficult to recruit participants for this study. With the non-attendance of 2 participants on the day of the focus group session, it resulted in a total of 3 members partaking from the same family. This focus group paved the way for some very interesting insights, perceptions and ideas among the carers pertaining to their relative's pressure area care. Of note, within the writer's journal their relative was being treated for grade 4 PUs to the sacrum and heels, the development of which did not occur in the acute site setting of this study. From the writer's reflective journal a more comfortable and detailed flow of conversation was identified among this group. The residential site once again proved difficult to recruit participants for the focus group. Three participants agreed to take part in the study however on the day of the focus group 1 carer could not attend, thus leaving 2 carer participants. 1 of these participants requested a separate interview as they did not feel comfortable in taking part in a group session. Subsequently, discussions with both participants occurred separately.

### **4.3 Awareness**

Collectively, the key objectives of this study were to assess the level of awareness, knowledge, involvement and understanding reported by patients and carers pertaining to the Quality Improvement Collaborative- 'Pressure Ulcers to Zero'(HSE 2013a) and the SSKIN care bundle (Gibbons *et al.* 2006) in PU prevention. A running theme throughout data analysis, that was evident during the interview process, was the level of awareness delineated by study participants. In the context of this study, awareness refers to the study participant's cognisance of pressure area care and pressure ulcer prevention as well as their level of knowledge and familiarity with the SSKIN care bundle and the Pressure Ulcers to

Zero Collaborative. The emergence of 3 sub-themes added to the validity of this main theme. These sub-themes include;

1. Awareness of Pressure Ulcers to Zero (HSE 2013a) and the SSKIN care bundle (Gibbons *et al.* 2006)
2. Awareness of Pressure Ulcers and Pressure Area Care
3. Readiness for Engagement

#### **4.3.1 Awareness of Pressure Ulcers to Zero and the SSKIN Care Bundle**

Foremost among the themes to emerge from the data analysis and indeed, that was evident from the time of data collection, was a lack of awareness surrounding patients and carer's knowledge pertaining to either the Pressure Ulcers to Zero (HSE 2013a) collaborative or the SSKIN care bundle (Gibbons *et al.* 2006). Out of the total 25 study participants only 1 patient knew about the Pressure Ulcers to Zero (HSE 2013a) collaborative. This was due to their participation in a video as part of the course work for the collaborative. Another 2 carers offered a vague awareness of its existence. The following quotation unfolds one such participant's knowledge.

*"Well, ... I did because I know they were doing courses and having training days and things like that. Is that what you were referring to?"*

Carer 1 PCA

During the interviews the writer also presented participants with the 'Pressure Ulcers to Zero' logo (HSE 2013a) in an attempt to elicit any recollection.

*Pressure Ulcers to Zero logo (HSE 2013a)*



The writer's journal recorded that the logo is located on the posters in the acute site, though in a small font on the bottom of the posters. However, most participants responded that they had never seen it before. Some participants revealed that they had seen it only recently, within the documentation the writer had given them pertaining to the study as identified in the following quotations;

*"No. No I wouldn't have known about that. No. No. Not until you came"*

Patient H Residential

*"No. Just on the one that you gave me last night. That's the first time I actually saw it. You know I didn't ever see that before."*

Patient L Acute

*"No. Only when you gave it to us"*

Carer 7 Acute

Similarly, only a small number of the total participants affirmed their familiarity with the acronym SSKIN or the concept of the SSKIN care bundle (Gibbons *et al.* 2006), with many once again outlining that they only heard of it through the writer's study.

*"Eh, it's, it's not, I think it's not widely spread you know, enough. I don't think an awful lot of people, I'd say if you were to ask the majority of this people in this room they probably wouldn't know what you were taking about. You know, maybe now, you know maybe or in any, I'm just taking this room, but I think it could be highlighted a bit, an awful lot more."*

Patient L Acute

The writer must point out that within the Primary Care Area (PCA), the team chose the acronym “PROMPT” for use as a care bundle in PU prevention. With its content mirroring the concept of SSKIN, the PROMPT (See Appendix 21) refers to:

- P= Pressure Points
- R= Red- Report it
- O= Oral Intake
- M=Moisture
- P= Position
- T= Take pressure off.

However, familiarity of this tool among patients was not demonstrated throughout the interview process, despite some PROMPT cards visible within the home setting during the writer’s visit. Once again the writer had shown the PROMPT cards to patients during the interview to elicit recall, but with mostly fruitless results. While some exhibited a knowledgeable account of pressure area care and PU prevention it was not demonstrated through the use of this acronym. It appeared to be more familiar to the carers, rather than patients. Indeed, it was acknowledged among carers within the focus group, that these PROMPT cards appeared to have been only recently been made available to them. Another carer confirmed that they had not been available last year, while caring for her relative during the start-up phase of the collaborative. A shared view among these focus group members was that these PROMPT cards were proving to be very useful as a reminder to family and ‘agency’ affiliated health care assistants (HCA) as illustrated in the following quote;

*“And the little reminders to put on the fridge or to put on the carers notebook to remind them. Yeah we have them all over the place so to remind everybody to keep an eye on it”*

Carer 3 PCA

Whilst these PROMPT cards may only have been recently made available, most study participants within the PCA voiced that information regarding pressure area



care had been given to them from the PHN and the HCA affiliated within the primary care health centre. This was more strongly felt among carers in this site.

As the main focus of this study revolved around the SSKIN care bundle (Gibbons *et al.* 2006), the writer maintained its concept throughout the data collection process to add rigor and validity to the results of the study. Therefore the writer continued to refer to the SSKIN care bundle (Gibbons *et al.* 2006) and each of its elements within the interview and focus group process in each site. To note, from the writer's reflective journal, there was much confusion surrounding the acronym SSKIN both in the preliminary meetings with individuals and in the data collection. Many participants, particularly the elderly, confused the acronym with their actual skin. Therefore throughout the interview process the writer had to re-iterate each letter and meaning of the SSKIN care bundle (Gibbons *et al.* 2006) to participants to ensure comprehension.

The majority of those participants with some form of awareness of the acronym SSKIN (Gibbons *et al.* 2006) originated in the acute site. Noteworthy, from the writer's reflective journal, when participants were asked at the beginning of the interview process if they had heard of SSKIN (Gibbons *et al.* 2006) they replied that they had not. Yet, later in the interview they revealed their acknowledgment of seeing SSKIN (Gibbons *et al.* 2006) on visual cues. This is reflected in the following quotations;

*"I didn't know what it was as I said at the beginning when I just saw SSKIN and I was saying why is it SSKIN? And I am going and that's what caught my attention and that's why I started reading about it you know. So."*

Patient L Acute

*“I only saw the poster when I was standing out at the glass on the corridor when they when they were changing \*\*\*\*\*(relative)and they asked would I go out to the family room. So I walked down and I was reading all the posters and I read that one and I said oh God because \*\*\*\* (sibling) had been saying about all those things on her arm and the swelling .....When \*\*\*\*(sibling) came in there was dents on the feet and she asked for the booties to be taken off immediately, and they did. But it was around that time that I connected with the thing that the poster was saying”*

Carer 7 Acute

While some participants reported that they were told about SSKIN (Gibbons *et al.* 2006) through both verbal and written methods, the majority voiced that they took note of it from the posters or visual aids around the ward. In addition these participants revealed that no verbal explanation had been offered by staff pertaining directly to SSKIN (Gibbons *et al.* 2006). On the other hand, some participants identified that, although they may not have been told directly about SSKIN (Gibbons *et al.* 2006), its content may have been relayed to them by staff in different meanings and terminology.

In the acute site the visual aids and information leaflets were reported by some study participants, to act as an aid memoire and assisted in increasing awareness on PU prevention. For some, when they saw the poster, they recalled previous personal experiences which served as a reminder for them to look after their own pressure areas. Noteworthy, when discussing the posters with participants, 4 patients made reference to the presence of two staff members modelling in the poster. Following a discourse on the information tools used in the acute site, participants felt that they were quite informative and helpful. For example one participant revealed how the information leaflet initially prompted them to mobilise, citing that;

*“.....a lot of these things can be a visual thing, it can be a much more effective communication that works....”*

Patient N Acute

The presence of badges with a 'Think SSKIN' logo on staff increased curiosity as reported by some participants in the acute site. Nevertheless, a sentiment that resonated among many participants was the need for more people to be told and informed of PU prevention and the SSKIN care bundle (Gibbons *et al.* 2006). Interestingly some participants elaborated on this concept incorporating how more staff should also be told about its existence. Carers in the PCA unanimously agreed that the 'agency' HCAs provided by outsourced agency services, should be educated more on the prevention of PUs. They cited the SSKIN care bundle (Gibbons *et al.* 2006) as a simple means to educate them. One patient in the residential site, when sharing experiences on their involvement within the video for the Pressure Ulcers to Zero (HSE 2013a) collaborative asserts;

*“to help maybe people that might think they know it all in a sense (smiles). Because you are a nurse or you're a doctor, you know it doesn't mean that you do know it all.....”*

Patient A Residential

Another patient reflected how a smaller version of the posters at each bedside could serve as a reminder for the patient and the nurse / HCAs or indeed other disciplines. In the PCA the carers commented how they felt the magnetic PROMPT card was proving a useful tool on the fridge, serving as a reminder for all family members and indeed 'agency' HCAs in the provision of PU prevention. To add, from the writer's journal, the PCA also had warning stickers for patients so that they could be worn on admission to A&E or any other unit to highlight to others that they are at risk of PU development. Many thoughts and ideas that emerged from participants on creating awareness and educating individuals in PU prevention and the SSKIN care bundle (Gibbons *et al.* 2006), included one to one information sessions, a video presentation playing on-site in the local family room, and photographs. While some were suggestive of a smaller scale in-house awareness campaign, others suggested a full national campaign on PU awareness, similar to that of the smoking and hand hygiene campaigns. Be that as it may, in essence communication of the bundle message was still deemed to be the most vital component.

#### 4.3.2 Awareness of Pressure Ulcers & Pressure Area Care

The data collection paved the way for capturing diverse concepts, ideas and perceptions from each study participant. Upon commencement of the data collection process, all participants were asked about their awareness and understanding of pressure area care and PU prevention. There were mixed views on the general awareness surrounding PUs. The following quotations show this:

*“But your average man on the street I don’t think knows about pressure sores”*

Patient C Residential

*“ Well em, you know, you can’t come to my age and meeting a lot of people who are bed bound and that kind of thing and hear about it and em, you know if you are listening you hear of people who are bed bound and have bits of problems with sores so.”*

Patient M PCA

*“I didn’t really know. I heard of them certainly, but I never seen one on anybody. I heard of them certainly, but I never, I just thought that they were pimples or something.”*

Carer 5 Acute

While reviewing participants’ narratives, PUs were more commonly referred to as ‘*bed sores*’ or ‘*pressure sores*’. While two patients referred to them as ‘*decubitus ulcers*,’ others dubbed them as ‘*skin rashes*’ or ‘*skin sores*’. One carer referred to PUs as a resemblance of cancer, in that it appears to spread. From the narratives it has emerged that most participants were aware of and understood that pressure area care was important, with many highlighting prevention as the cornerstone in avoiding PUs. Surprisingly, it was noted among 2 carers within the acute site, that they believed PUs could not be prevented; however, their thought processes appeared to change as the interview progressed. This is reflected in the following excerpts;

*“.....and how to treat that I do not know. Or to help it even. I don’t think you can prevent it. It’s just part and parcel of what’s going on in your body.....”*

Carer 6 Acute

Then later in the interview:

*“ Whereas if the communication was there and they said to you ‘your \*\*\*\* might develop a sore and we want to prevent it, this is how’ well sure that would change everything”*

Carer 6 Acute

The majority of participants commonly agreed that PUs occur in the elderly or those that are immobile or bed bound. Although some participants shared different views about the location as to where PUs may occur on the body, the general consensus was that they occurred just on or above the buttocks. Noteworthy, many participants referred to getting a PU on your ‘*back*’, yet further probing by the writer identified that it was the sacral region that they were referring. The level of understanding and knowledge varied among participants. This was most pronounced when one participant thought that a bed sore and a PU were two different things. Additionally, this patient focused on areas of development of a sore where excoriation or moisture lesions are most likely to occur such as under their breast and perineal/groin area. An example of another participants’ understanding of PUs is illustrated in the following quotation;

*“I didn’t know they were such a serious thing and I wouldn’t have known the signs that it was going to become one.”*

Carer 6 Acute

On the opposite end of the spectrum, the data revealed that some of those participants, who had previous experiences of PUs, whether through personal or employment experiences, demonstrated a greater awareness pertaining to PUs and associated prevention techniques. Their increased awareness was predominantly due to the negative exposure they endured as a result of the PU.

The following quotations provide us with a glimpse of some participants' experiences;

*"I didn't realise how serious a pressure sore could be. But it is only from experience that you find out really." ..... "So that was my first em, terrifying experience"....."And on the outside it looked like a pinhole and in the inside it can be a big huge thing and you don't even realise when you are looking in at it on the outside that it's only like a thumbnail and you go inside and clean that out, it could take 3 months. Like that's literally what it did. And I think that really opened my eyes anyway I tell you."*

Patient A Residential

*"It's so easy to get them if they are not looked for and so unpredictable quick..... So unpredictable. I've seen it. Not here today and there tomorrow. I've seen how easy it is, if the person's skin is as you say broke down, it will go for it quicker. If you skin is not working and your skin is not as the end one, hydrated and all that there, you will get it quicker"*

Patient J Acute

*"I got one on me heel before. It was very, very sore so. Well it went straight to the bone and it took about a year to get rid of it. So, I know quite a bit about pressure sores"*

Patient O Residential

For these participants, among others, they felt that their previous experiences contributed to their awareness and knowledge of pressure area care and PU prevention as the following excerpt shows;

*" If I didn't know as much, then I would have come into it blind sort of, and relied on people telling me and to do it. So I had a rough idea, sort of it. It sticks in there when it comes a time for yourself to be that wee bit more about your skin."*

Patient J Acute

Several participants divulged that they had previous employment experiences within the health sector at some point in their life, which they felt contributed to their awareness and knowledge of PUs. One participant remembered a time in their life where they previously worked as a hospital porter. They recalled assisting a nurse to turn a patient who had a PU on their back that was the size of a fist. Another participant attributes their knowledge of PUs from their days in the ambulance service.

*“I think the biggest thing you can do, if you’re aware and as I said my job has made me very aware of lots of things that I never thought that it would play big part in my life, on a personal basis to be honest with you. But when you are aware of that and you see it, you just know if there is something going wrong or if there is something not right. I just feel I know and if \*\*\*\*(spouse)complains in any way to me, ‘oh my elbow or my back or whatever’ and I’d have a look or I’d get them to have a look for me.”*

Carer 8 Residential

Several of the carers that took part in the study illustrated a good awareness and comprehensive understanding of pressure area care and PU prevention. However some carers within the acute site felt that whatever knowledge they had was acquired as a result of their relatives’ condition who, at the time of data collection was being treated for grade 4 PUs. The following quotation is an expression of their feelings about this.

*“I think it’s sad to be left with a regret. To the way we (the family) are, that we didn’t know and that maybe we didn’t ask the right questions to begin with”*

Carer 7 Acute

#### **4.3.3 Readiness for Engagement**

Progression in recovery for patients appeared to be a contributing factor in their awareness of pressure area care and indeed their acknowledgement of PU prevention. For some participants they felt that pressure area care was not something they considered, especially pertaining to surgery. This was indeed

evident for the writer in the recruitment process, when 2 potential candidates identified by the gatekeeper, declined to take part in the study. They believed they had nothing to offer, given that they were in the pre-operative stages of treatment, fully mobile and therefore considered that they would not be at risk of a PU even after surgery. Alternatively, patients may feel too ill to be concerned. One patient, who on a previous recent inpatient stay, had been hospitalised for an extended period in the acute setting imparted their early memories of recovery;

*“Like in the early stages I wouldn’t have had the interest or the strength. You’re head wouldn’t have been in that zone. Em, I was too sick to realise what was going on, the first couple of months so. No I think the information is there, to be read. A person just mightn’t be able to do it or read it, at certain points of their illness so, like if you are too weak to even think about breathing for yourself. You’re too weak to breath. It comes back down to the first line of defence again which is the nurses to inform you in as gentle a way as they can, ‘we have to move you to make sure that you don’t get bedsores’, simple as that, you know.”*

Patient F Acute

This sentiment resonates among other study participants. Another participant recalled how they saw the nurses in the ward wearing badges that had a ‘Think SSKIN’ logo on it and wondered what it was. When the writer asked if they had ever enquired as to what it was, their reply conveyed a sense of apathy.

*“I wasn’t in the sort of mood to ask them”*

Patient K Acute

One study participant who received both verbal and written information on SSKIN remarked that they would have liked to have been informed about it earlier, but acknowledged that when you come out of an operation you are in no condition to absorb the information. The following excerpt describes this patients’ post-operative encounter;



*“A lot of the work if not all of the work is done by the nurses because they are turning you and they are changing you. They are checking you, so in the sense that the principles of SSKIN were applied but I wasn’t conscious what it was SSKIN being done. But as I came through the later stages of the process, clearly I understood then. So I think em, it was probably, the approach was probably the practical way of approaching it because as I said already you are not really first of all capable of absorbing the information not alone implementing it”*

Patient N Acute

Another study participant who had significant paralysis recalls how when they were initially discharged home from hospital PU prevention was not to the fore of their mind as they were concentrating of lifestyle choices, which resulted in the development of a grade 4 PU. The following excerpt reflects this;

*“but when you leave the rehab you don’t realise all them things at all, even though they might have said it to you, but it kind of went in one ear and out the other, you just wanted to get home”*

Patient A Residential

During the interviews several participants in the acute site reflected on how pressure area care was not deemed a priority in the initial stages of their stay due to the severity or nature of their medical condition. Yet it was something that they became more aware of and took precedence as they progressed in their recovery, more so in the latter stages of their stay. As such, there appears to be an element of readiness by patients to engage in PU prevention as they became less ill. Carers within the acute site referred to their experiences and how their level of awareness of pressure area care increased throughout their relatives’ trajectory of care, in which they noticed a gradual decline. They discussed how, as family members in the beginning, their attention centralised on their relatives’ surgery or medical condition. However as time progressed, the shift in focus of their relatives care surrounded the management and treatment of PUs which had developed on their relative’s sacral region and heels, thus increasing their awareness pertaining to pressure area care.

#### 4.4 Patient Involvement

Coupled with the confusion that surrounded the acronym SSKIN (Gibbons *et al.* 2006) and because many participants were unaware of its existence or its totality as a care bundle, the writer broke down each component of the SSKIN acronym and discussed the individual elements with participants. The writer then phrased questions to incorporate the participants' role within pressure area care based on the SSKIN care bundle (Gibbons *et al.* 2006) and assessed their involvement in each component or indeed in the overall bundle of care.

For the purposes of this study, 'patient involvement' delineates the patient participants' perceptions of their level of involvement within their own pressure area care as well as pressure ulcer prevention interventions through the use of the SSKIN care bundle. Interestingly, there were some mixed opinions among patients pertaining to their level of involvement in pressure area care and within the SSKIN care bundle (Gibbons *et al.* 2006). From the narratives, it appears that those with a greater awareness of PUs, whether through personal or professional experience, were more involved in their own pressure area care. Indeed, some participants reported that staff made them feel involved in PU prevention through communication. On the other hand, the majority of patients highlighted that they did not feel involved because they were not told anything about pressure area care or the SSKIN care bundle (Gibbons *et al.* 2006). In the same breath they revealed that they would have preferred to have known about PUs and the SSKIN care bundle (Gibbons *et al.* 2006) sooner, prior to the study.

It became evident particularly among the patients within the acute site that the role of pressure area care was taken over by patients from the nurses as part of their recovery. The following quotation reflects this;

*"At the start I can't say, but as time progressed em, I became eh, more physically able to move around myself so I kind of took over the role from the nurses in a funny kind of sense...."*

Patient F Acute

Another reason that patients provided regarding their level of involvement, was as a result of their own preference and decision making. This was primarily due to previous past experiences and fear of developing a PU, as demonstrated in this quote;

*“I’d say that would have been down more to meself. ....But then again as I said to you, if I hadn’t have seen it first hand, I wouldn’t have known. Just because I seen it first hand and seen how simple it could start, I took that care.”*

Patient J Acute

Following further review of participants narratives, three distinctive sub-themes emerged which assisted in the formulation and endorsement of the main theme ‘Patient Involvement.’ These subthemes include;

1. Control and Dependence
2. Patient Preference and Decision-Making
3. Increased Responsibility.

#### **4.4.1 Control and Dependence**

Across the range of settings, nearly all of the participants acknowledged that they relied on others, predominantly nurses, to some extent in the provision of care. Consensus existed among all patients that they had either limited or no control over viewing particular parts of their body as a result of restrictions, due to medical conditions, illness or post-operative status. Hence they relied on staff to perform a skin inspection to monitor for any indication of PU development, many of whom identified this as a priority.

Mobility was also deemed a concern by many and was seen as being out of their control as a result of their condition or due to a change or decline in their illness or status. This was most pronounced in the residential setting, where patients interviewed were paralysed or had poor sensation, limited functional mobility and were wheelchair bound and most of whom (all but one) identified that they were at risk of developing a PU. While some acknowledged that it was important for them to look after themselves, a shared view among these participants was a reliance on nurses and carers to perform physical tasks in their trajectory of care. As a

result, some participants within the residential site disclosed that they felt they had limited involvement in pressure area care, pertaining especially to skin inspection, mobility and at times incontinence. One such participant's comments reflect this.

*".....I'd say there is about 12 or 13 people that wouldn't know it, that wouldn't know like meself, that would have poor ability in knowing when you are getting a sore, so other people would have to watch that for you."*

Patient O Residential

Nevertheless, during the interview process this patient population exhibited a strong sense of empowerment. In essence, participants acknowledged that part of their role as a patient or resident would be to eat well and also to inform staff of any pain or discomfort they may be experiencing. Indeed, they seemed to take ownership in communicating their need to be moved or be repositioned within the wheelchair or bed. Communication with staff allowed for self involvement in the decision making process. As it was an important aspect of their day to day living, they also relayed that if they required any assistance regarding their wheelchair or cushions they would seek and request to speak with the Occupational Therapists. One participant, who previously experienced a PU, conveyed their ability to take control of their pressure area care. One example that they provided involved viewing a photograph of their sacral region especially if the staff alerted them to any redness. Subsequently this contributed to the participant becoming involved in the decision making process for the most appropriate course of treatment as the following excerpt shows;

*"I would negotiate the thing, like you know, they would say maybe you could get up for today. There is no such thing as 'maybe get up for today'. I'd prefer to stay in bed for today and get up tomorrow, you know, and see what it is like. I suppose, I would take a certain amount of control about that, you know, that when they show it to me, I would say God that looks a bit red still. Like you know, kind of more control it in a sense that way, once I'd see it."*

Patient A Residential

Some of the patients interviewed in the PCA received meals on wheels which they acknowledged allowed for a healthy balanced diet, while others had either live-in carers or carers that called once or twice a day. These participants emanated a sense of reliance on these carers for hygiene needs and a skin inspection. One patient humorously expressed;

*“Well you know I am helped to shower, so people who are dealing with me have a pretty good picture of my beautiful body (laughs)”*

Patient M PCA

The same patient later described in the interview how, as part of their role, they take control of the situation;

*“ ....it’s up to me if my carers don’t take note, to remind them that. And eh, I do that. Some days I’d say to whoever would be looking after me, I think my bottom feels a bit sore today, would you just check that there is nothing going on...”*

Patient M PCA.

This sentiment is shared by other participants within the PCA. All patients further expressed that they were happier when the PHN reviewed their pressure areas also, which occurred on a regular basis, with visits increased should the need arise due to the detection of areas of redness. However one participant expressed how they did not have any carers or family members to check their pressure areas and divulged a sense of fear of getting a PU because of this. Consequently, the participant relied on the PHN but acknowledged that as part of their role, they must mobilise and reposition themselves whether in the bed or chair as recommended by the PHN and liaise with the PHN to examine their skin.

Others in the PCA reflected how they had no control over the decline in their mobility due to their medical conditions, hence restricting their ability to adequately mobilise or reposition themselves in bed or in the chair. What was interesting to note though, for two of these patients, at the beginning of the interview they did not deem themselves at risk of a PU simply because they had never experienced one.

But as the interview progressed they acknowledged that this was an important factor in the development of a PU thus placing them at risk.

Within the acute setting all patients conveyed that in the early post-operative stages they experienced minimal self control, with profound reliance on staff and carers for a multitude of activities pertaining to pressure area care, most notably, skin inspection, hygiene needs, repositioning and mobility. This was primarily due to their inability to perform tasks for themselves. In fact one participant strongly expressed that they were somewhat vulnerable, as there were many elements that were out of their control including their reliance on intravenous nutritional support. Other contributing factors inhibiting involvement in pressure area care as described by other patients included sedation, overwhelming tiredness, pain, perspiration, the presence of an epidural infusion, the wound and/or stoma site, and the presence of medical devices such as chest drains, nutrition and hydration support via central venous catheters, wound negative pressure devices. The following quotation provides us with an indication of the dependency concept;

*“ ....like if you are just lying there with all those things, all those tubes on you like you know, it's up to, well there is nothing you can do really like. It's up to your carers. You're care is in someone else's hands. That's the way I look at it....., you can't turn or look and see if I'm sore or are me feet sore.....You're tired and you're lying there and you are depending on other people to do their job.”*

Patient I Acute

Although some patients in the acute site shared different views about how they were made to feel involved in their own pressure area care throughout their inpatient stay, most agreed that in the early stages of post-operative recovery, their role as a patient involved co-operation, listening to what the staff told them to do and informing staff of any pain or discomfort. As patients progressed from the higher dependency units to the ward setting, some patients voiced their frustrations about having to rely on staff, as at times they had to wait for a nurse to come to their assistance especially when it came to repositioning in the bed. Ultimately their level of reliance on staff then diminished once they were detached

from any medical devices and they were able to mobilise and perform simple tasks for themselves, thus reclaiming control and independence.

#### **4.4.2 Patient Preference and Decision Making**

Patients who had some form of personal or professional experience pertaining to PUs reported feelings of nervousness that prompted engagement with PU prevention interventions. It became apparent during data analysis that these patient experiences influenced their decision making which led to them becoming more involved in their own pressure area care. The following quotation provides an understanding of the participants' perception;

*"....the nurse told me that I was to put a cushion under my feet in bed so that my heels would be hanging out over the cushion and that did help.....I did do it and that helped so, I got great relief those nights.....it would keep the pressure off my skin and off my heels and that they wouldn't be, well the blood would be getting to that area. And well, to prevent anything worse happening, having an ulcer or the skin breaking, and em, getting an ulcer, which I would dread. (Sighs) Because my \*\*\*\*(relative) had one years ago and it went on for a whole year, so I know how much time and how, how much I don't want an ulcer. I want to avoid it at all costs"*

Patient H PCA

For the majority, as part of their role, patients emphasised the importance of mobility in pressure area care. However, it was interesting to hear how many patients referred to being '*stuck in the one position*' in either the bed or chair and the level of discomfort they experienced. As reported, patient preference appears to have evolved mainly from the patient's inability to get comfortable and the difficulty they experienced in repositioning themselves in the bed or the chair. This appeared to be a common concern, nevertheless many of these patients revealed that they would voice their concerns to the staff and communicate their preferential position in order to experience comfort, relieve pain and indeed as reported by some, '*to relieve the pressure*'. For this reason, some patients appeared heavily involved in this decision making process pertaining to the positioning of pillows,

the position of limbs, the height adjustment of the bed or chair and indeed the need to either sit out or return to bed. The following patient statements are an expression of that engagement;

*"I find it hard to sit out. I don't find that it gives me much relief at all, it just aggravates my back more and em, that's why I prefer to come back into bed and try and sit myself into a position or get myself into a situation where I am a bit more comfortable"*

Patient L Acute

*"....Position is everything. Eh and even when I am up now and I'm even in the power chair and I'm paralysed from my neck down, I would ask people to kind of move my leg or to move my body or you know that I can move a bit, it's not as if I'm sitting from the time that I got up this morning in the one position. I'm moving as well, even though I am not walking, I'm moving"*

Patient A Residential

In contrast, it was revealed by some patients within the acute site, that there were times that they did not understand why nurses repositioned them frequently despite being in a comfortable position. No explanation was communicated as to why this was happening. This was experienced across the transition of care from the higher dependency units to the ward. One patient in particular reflected how although they did not understand, they knew there was some reason as to why it was being done and that the nurses were doing their job. Another participant shared this sentiment following on to say that if they had known more *'you'd have it in the back of your mind'* (Patient K Acute), signalling that they would decisively participate more in repositioning thus in their pressure area care. Also within the acute site, almost all (bar one) of the patients were nursed in old style hospital beds that had to be manually adjusted if they so wished to sit up or lie down, thus relying on staff and limiting their self involvement in pressure area care. These patients spoke of their dissatisfaction over this and relayed that they would have much preferred a remote control style bed (which they had experienced when nursed in the higher dependency units) which they unanimously felt, would allow



them to decide on their preferred position in the bed as well as promote ease in repositioning and comfort.

Another preference cited by patients in this site was to have an air cushion to use when sitting out. There appeared to be a lack of air cushions available to patients. Indeed one participant asked of the writer in the interview did such a thing exist or could a balloon ring be used to take the pressure off their sacral region as would have been their preferred choice. Following a discourse on the existence of pressure relieving cushions and an explanation given as to why balloon rings are no longer endorsed, the patient subsequently asked why they had not been offered an air cushion. They relayed that they would have like to have had the choice to decide in aiding a preferential comfortable position when sitting out. They further asked the writer to relay this back to the staff on the ward.

In the PCA, patients appeared to have made conscious decisions regarding adaptations to their home, sourcing different forms of medical equipment, with '*a view to the future*' (Patient G PCA), in preparing for the eventuality of becoming more immobile or deteriorating due to their medical conditions. Most acknowledged that the PHN and Occupational Therapist were involved in their care and performed continuing assessments in the need for any further equipment. However many reported having these adaptations made of their own accord, prior to any primary care team involvement. One patient went so far as to have remote control curtains and lights installed to help reduce the risk of falls and to prepare for the potential prospect of becoming bedbound. However, some patients disclosed that despite the presence of these adaptations and medical devices, they preferred not to use them until absolutely necessary.

Participants within the focus group in the PCA also alluded to this belief among their loved ones or person they cared. In the focus group, they identified that their loved ones or person they cared, at times made preferential decisions more so relating to medical equipment, predominantly the hospital bed. This occurred despite recommendations by the PHN to allow ease of comfort and assist in pressure area care. An example of one such patients' ideology follows;

*“You feel you’re worse than you are you know, when you have something like that. I don’t believe in meeting those kind of things before I need to, but I know it’s important to have a good bed, for everyone.”*

Patient G PCA

Whilst nearly all patient participants acknowledged in some format that the standard of care they received was of a high level, a recurring preference voiced among numerous patients was of their wish to receive earlier awareness and more information pertaining to pressure area care and to that of the SSKIN care bundle (Gibbons *et al.* 2006) as the following quotation exhibits;

*“I wish I had heard about it earlier. Because years ago I was a dead ringer for one. I’m not now, I don’t think. Touch wood. Or am I? (Smiles)”*

Patient C Residential

It became apparent as the interviews progressed, when pressure area care and the elements of the SSKIN care bundle (Gibbons *et al.* 2006) were broken down and discussed, the majority deemed the SSKIN care bundle (Gibbons *et al.* 2006) to be a good idea. Indeed this is well captured by one of the patients;

*“I think that it’s very good. It’s a good bundle to use as a set of criteria to watch out for the skin. You know?”*

Patient P PCA

Furthermore, it was expressed by some, predominantly within the acute site, that they would have preferred to have known and be told about the SSKIN care bundle (Gibbons *et al.* 2006) sooner, with a greater emphasis to be placed on the importance of pressure area care. They conceded that PUs and pressure area care was not something that they thought about. In addition, for some, it was reported had they known about it sooner and received more information, they would have acquired a greater understanding, co-operated more and taken more responsibility upon themselves in preventing PUs.

#### 4.4.3 Increased Responsibility – “doing what you have to do”

Data analysis revealed those who had previous past experiences relating to PUs, demonstrated a sense of empowerment through an eagerness to take responsibility in their own pressure area care. Most notably this was achieved by taking control, performing activities such as mobilising and hygiene needs, more readily and routinely (especially in the acute setting in the post-operative period), and making decisions about their pressure area care. Patients who had been informed about pressure area care showed similar patterns. One patients' experience of adapting to perform tasks independently thus increasing her responsibility is captured in the following excerpt;

*“.... so I did it yeah, when they tell you, you just don't want them to come. And you do what you have to do”..... “Well they make you feel involved, like they say to you and like you kind of say well ok that's it, you don't want it, so you keep your feet up”..... “I don't mean it in a bad way but they do nag you (laughs) but it was the only way out”*

Patient E Acute

Interestingly, numerous patients, more so within the residential site and the PCA, recognised that although they required assistance with physical needs, they referred to part of their role as looking after themselves, thus implying their decision to take responsibility and contribute to their own care. Fundamentally this indicated a sense of patient involvement. Indeed one patient participant in the residential site discussed how as part of looking after themselves, they kept themselves informed. Another patient within the PCA acknowledged their responsibility of their own pressure area care as indicated in the following statement;

*“I am conscious of the fact that I have to look after my skin.”..... “ So I have to put a bit of effort in too. But that's all I have to do is to look after myself. That's all I can do.”*

Patient M PCA

Within the writer's reflective journal reference was made to a stronger sense of responsibility and empowerment that emanated from patients within the residential site and the PCA.

From the narratives it could be seen that, as the interviews progressed and as a discussion unfolded surrounding each element of the SSKIN care bundle (Gibbons *et al.* 2006), several patients displayed some form of recognition of the need to take responsibility in the provision of pressure area care. Variation occurred among the patient population with mobilising or repositioning, verbalising concerns to staff and maintaining hygiene the most common attributes listed. One acute hospital inpatient identified how as a result of talking about PU prevention and the SSKIN care bundle (Gibbons *et al.* 2006), it changed their perception of their own involvement in pressure area care as the following excerpt shows;

*"I'd be more responsible now, you know. More responsible, compared to what you were because you think coming in you are lying in bed and you think nothing is going to happen to you. You know that kind of a way so. You'd be thinking about it more so now."* As the interview progresses, they discuss how other patients should be informed *"....but they should know themselves, like you know, it should be told to them you know that sort of a way. It's sort of like adding responsibility onto the patient like than having it all on the nurse"*

Patient K Acute

This sentiment is echoed by another patient within the acute site who strongly believed that patients should be more responsible in their own pressure area care. The relationship between the patient and the nurse is described as a "two way street" signalling that;

*".....it's part of the patient's responsibility to well, to take responsibility for parts of their own care as well, particularly when pressure sores are at risk"*

Patient N Acute

#### **4.5. Family/Carer Involvement**

One of the overarching objectives of this study was to gain insight into the level of involvement of both the patient and family/carer within pressure area care and PU prevention through the SSKIN care bundle. In the context of this study, this theme focuses on the findings of family member's/carer's involvement as depicted within the participants' narratives. In essence, data analysis showed a variation in the levels of carers' involvement in the care of their family member or person they care for across the range of settings. However the writer acknowledges within her reflective journal that the different levels of care provided by carers were owing to a variety of reasons, for example, the location of the relative and their level of dependency and whether the carer lived with their family member. Carers' involvement is characterised within two sub-themes which have emerged from the narratives;

1. Primary Caregiver versus Visitor
2. Seeking More Involvement.

##### **4.5.1. Primary Caregiver versus Visitors**

Family members across the range of sites had different views and perceptions on their level of involvement within their relatives pressure area care. One family member reflected on how;

*"I don't think people realise what's involved in looking after somebody who's in bed all the time"*

Carer 9 Residential

Within the PCA 2 family members perceived themselves to be more or less fully involved in their relatives pressure area care, while another reported how, because they did not live with her relative, this limited their ability to be fully involved in their relatives pressure area care. Whilst acting more as a 'visitor' they reveal how if they are not in the presence of their relative, they would continue to perform tasks such as keep phoning them and tell them to move.

When focus group members in the PCA were asked about their role within PU prevention a consensus emerged that they felt they managed it very well but

acknowledged that monitoring their relative/person they cared for and accessing support from the PHN if needed were contributing factors. Overall family members within this site displayed a good understanding and awareness of PU prevention, describing the different techniques adopted and care they provided upon discussion of each element of the SSKIN. They attributed much of their knowledge to the education and information given by the PHN and carer affiliated with the local health centre. Some reliance was placed on the PHN pertaining mostly to skin inspection and surface equipment.

Throughout the discourse of this chapter reference has been made to the presence of a privately employed live in carer among focus group members in the PCA. Data analysis has revealed that this carer was heavily involved in the care of the patient, performing and assisting in most activities pertaining to pressure area care, signalling that they were the primary carer. Emanating also from the narratives, was their rapport and involvement with the patients' family members whereby the carer reported to them any concerns they may have had pertaining to their relative. The following is an indication of this;

*" I think mostly some elderly might not like to drink water, like my woman. She drinks only one beaker a day and it's not enough really. So I ask them, (family) to buy orange, ice cream or hot chocolate or milk to take fluid."*

Carer 4 PCA

A strong sense of appreciation was evident towards the PHN, with a distinct level of trust exuding from each participant within the focus group in PCA. As reported by the family members in the PCA, they received additional support in the care of their relatives through carers from an 'agency'. However a lengthy discussion occurred within the focus group surrounding the topic of these carers. Family members felt that they had to continue to be proactive in the care of their relative even still when the carers were there. One family member reported how she had to keep reminding them to check their relative's pressure area as shown in the following quotation;

*“I feel I have to keep reminding them to check for things, I feel like I am on their back the whole time- ‘don’t forget to do this’- and I have more notes all over the house you know ‘don’t forget to do this,’ ‘please do this’. So you know I have to keep on at them about pressure sore sites”*

Carer 3 PCA

From the narratives, it can be clearly seen that despite some offering of help from external sources, the family members within the PCA were the primary caregiver for their relatives.

Data analysis revealed a stark contrast in the other two settings compared to that of the PCA pertaining to family members’ involvement in their relatives pressure area care. All family members within the acute and residential sites conveyed how previously, they had done almost everything for their relative when they had lived at home with them. It was revealed how they now felt that they had limited involvement and control over what care they could give, many wishing they could do more for their relative. One family member discloses how as part of their involvement in their relatives pressures area care, they come in most days and through observation is fully aware as to what is going on.

When family members were asked about their role in PU prevention for their relative, their responses showed a significant difference to that shared by the family members in the PCA. The following quotations, give a glimpse of their thoughts.

*“Well, I don’t have a role anymore. Sure I don’t? I just come into visit”*

Carer 8 Residential

*“...we were out of control when me \*\*\*\* (family member) came into the hospital. We, our role diminished. So we became her secondary carers rather than her primary carers so the book stops with them really. In terms of my role, I feel, I mean if we had the authority, I would have took me \*\*\*\* out of the chair meself. We would have had no problem doing anything. But we are in the thing that we were the second soldiers in that the hospital had the full control. And if anything happened me \*\*\*\*\* then we would have been responsible. We are visitors to a hospital, there is health and safety, there's all sorts of things. If we breached a certain barrier or anything, we would have been, well I would have been very aware that you know, the book stops with the hospital.”*

Carer 7 Acute

Other perceptions of family members' roles included alerting staff, provide emotional support, complaining if the need arose and assist with nutritional needs and preferences.

The decline in a relative's condition was referred to by some as a contributing factor towards their level of involvement in their relatives pressure area care. Limitations in family members' involvement of care were again evident when family members discussed how they waited in the family room or corridor while nurses tended to their relatives hygiene or toileting needs. For many of the family members within these 2 sites, they reported how nurses primarily tended to their relatives pressure area care and praised the nurses for the work they do in this regard.

One of the family members in the acute site reported how more feedback from staff would be most beneficial to them as a family unit on the progress or decline their relatives PU wound as she felt it would keep them more informed. Further discussions on this revealed how they felt more communication in general is warranted. The following excerpt reflects this concept;



*"It's information. You know when they go in and they change \*\*\*\*\* (relative) and they put in the medication and do their bits, you might be standing outside waiting. You know if somebody said, you know 'how is she?' or 'well that's a little better' or 'that's a little bit worse'. Common talking, not medical talking. Just to talk say to you. Do you know? Put you in the picture."*

Carer 5 Acute

In contrast, family members within the residential site report that they are kept well informed by staff members pertaining to their relatives care and indeed their pressure area care.

#### **4.5.2 Seeking More Involvement**

For some family members it is evident that they would have liked to do more for their relative and indeed to be more involved in their pressure area care. Within the acute site, family members highlighted their desire for a hospital policy that would allow all family members to be more involved in their relatives care. They felt that if family members were allowed to do more, it would be beneficial to their relatives and indeed to staff. The following is an indication of this concept;

*"...I mean there's a whole load of measures that they are using for them. But if staff said to us, you's are at the bed all the time, and we are up to our eyes, there's a jar of cream you are allowed- You see I don't know the health and safety but if there was a role that hospitals allowed families to come in and do something."*

Carer 7 Acute

The request of further information and continued communication with staff has been illustrated by all family members as ways to which they can maintain involvement in their relatives pressure area care. One family member in the community reflects on how as a caregiver, they would like to receive more information on range of movement exercises for their relative to maintain muscle tone in an attempt to avoid a further decline in mobility.

From the narratives, one of the factors that some family members felt they could contribute most to in their relatives PU prevention, was to assist in meeting the nutritional needs of their relative. Within the acute site, this was something that the family members sought to take ownership over when it was communicated to them by members of staff, how nutrition plays a significant role in the healing of PUs of which their relative had. Therefore, they had devised a rota amongst themselves to ensure that somebody was there to assist their relative with all meals. They also brought in some of their own food of which their relative may prefer and took note in a diary of what she ate thus allowing information sharing between family members. A close rapport was established with the dietician with one family member reporting that they spoke with the dietician regularly.

This sentiment resonates among other family members within the residential site, whereby they brought in suitable drinks and fruit. One family member communicated how they come in to assist their relative with their dinner most days and indeed goes to great lengths to find the most preferential and suitable drinks for them to drink, which at times proved difficult. This same family member reports how although they no longer provide the same level of care to their relative that they used to they still view themselves as; *“the head of the situation”* Carer 9 Residential. Hence requesting and seeking all communication and concerns regarding their relatives care are to be addressed directly to the them and not to other family members. Nevertheless, their appreciation, rapport and level of trust in the unit staff are evident within the narratives, as revealed in the following excerpt;

*“ I don’t you can beat it, you know, really and truly. From what I have seen and what’s here and the way \*\*\*\*\* (spouse) is looked after, when I go out of here now, I’m content to know that \*\*\*\* (spouse) is looked after. That’s the bottom line isn’t it?”*

Carer 9 Residential Site

#### 4.6. 'Prevention is Better than Cure'

The theme 'Prevention is Better than Cure' reflects the study participants' perceptions and their level of understanding on PU prevention. Throughout the data collection, this idiom was versed by many participants, thus lending support to its place as a prominent theme in the context of this study. One of the key objectives of this study was to acquire an understanding of participants' (patient's and family members/carers) knowledge and perception pertaining to the role of prevention in pressure area care. This objective incorporated participant's views on the effectiveness of implementing the SSKIN care bundle (Gibbons *et al.* 2006) in preventing PUs. Data analysis identified 2 participants who believed that PUs could not be prevented but acknowledged later on in the interview process following discussion of each element of SSKIN, how prevention would be seen as important. Nevertheless the majority of participants believed that prevention plays a vital role in pressure area care. In fact when asked about their understanding of pressure area care, prevention was conveyed by many as the primary facet in pressure area care, this was identified more so among those participants who had increased awareness or previous personal/employment experiences.

For those study participants who exhibited limited knowledge or awareness pertaining to pressure area care or PU development, they deemed prevention to be an important factor, even though some were unclear as to how some prevention techniques may occur. Interestingly, the writer noted, particularly during the recruitment phase and indeed during some of the interviews, that participants sought further knowledge and information from the writer regarding sites where PUs could develop and further ways in which to prevent them. As previously mentioned, the idiom '*prevention is better than cure*' was quoted by numerous participants throughout the discourse of the interviews, thus emphasising a recognition and understanding of the lasting results PUs could impose on an individual. The following quotation provides an understanding of this perception;

*"I've always known that they are almost impossible to cure, that it's better to, well ...prevention is better than cure. And that's why I am really very careful about that now"*

Patient H PCA

Despite the named theme evolving from participant's perceptions and use of idiom, two subthemes lend support to its origin.

1. 'Being in the comfort zone'
2. SSKIN as a preventative tool

#### **4.6.1 'Being in the Comfort Zone'**

Data analysis revealed how many study participants referred to the importance of comfort when discussing pressure area care. Some patients spoke of how if they relieved the pressure, and their skin was protected from the development of a PU, their comfort would be guaranteed, as indicated in the following quotations;

*"Well if I can avoid the problem, skin problems, my comfort is always assured, you know and it's as simple as that really."*

Patient P PCA

*"To make yourself comfortable, you have to make your skin comfortable."*

Patient J Acute

On the contrary, for others there appeared to be a distinct correlation between comfort and PU prevention. The following is an expression of that concept;

*"I think comfort is so much to do with it like. Get in a position, your body in a position where, where it takes the pressure off the points. Do you know what I mean like? Because every time they moved my pillows it seemed to relieve the pressure point for a while anyway."*

Patient I Acute

Within the acute site, many patients expressed their difficulty in getting comfortable in the days following surgery. For some this was attributed to the pressure they experienced over bony prominences, predominantly over the sacral region. The surface to which they were lying or sitting weighed heavily on their inability to get comfortable as did the restricted mobility due the presence of

medical devices, an epidural and post-operative wounds. Many referred to how they felt like they were '*stuck in the one position*' thus necessitating their need to be repositioned regularly to take the pressure off these areas, with further measures taken, to sit out for short periods in an attempt to promote relief and comfort. One patient asserts how;

*"It's just trying to get it all adjusted right"*

Patient K Acute

Patients could not give a full account as to what position they found most comfortable while lying in bed, but many identified that if they had had an electronic bed where they could have taken control of their positioning, they felt that would have assisted greatly in ease of comfort. As a result of their inability to get comfortable, many recalled how this interfered with their sleeping pattern which in turn led to feelings of frustration and anguish as reported by some. The following excerpt reflects one patient's experience;

*"you'd be just going, wouldn't you love just one of those floatation tanks. Do you know what I mean? That you would have no pain, no soreness you would just, you know just lie there and sleep and float. That's the way I felt I wanted it to do like, you know what I mean? Just like a bag of air or something. You just want to float away in it, to take the pain away and the discomfort. But do you know what I mean, imagine a floatation tank (arms outstretched, eyes closed) It's just there like and you would be so sore on your back for so long. You're lying there in a kind of water, lying on your back and you are floating along with no pressure, no pain. It would be heaven."*

Patient I Acute

For many patients, keeping the '*pressure off*' was recognised as a means of promoting comfort. One participant communicated how they could not sit for long periods as they felt their "*bones were sticking out through her skin*" (Patient P PCA) Another expressed how following the advice of the PHN by offloading their heels at night she found a significant difference to her level of comfort and proclaimed "*I got great relief those nights.*" (Patient H PCA).

A consensus existed among carers within the PCA how they believed their relatives/person they cared for, were most comfortable when they lay in the position they enjoyed all their lives. The following excerpt demonstrates this;

*"I'd say it's the position that they enjoyed all their live. You know a person that sleeps on their side whether it's their right or their left, it's being in their comfort zone. And I don't think that changes much when you are dependent"*

Carer 1 PCA

Carers within the acute site attributed their relatives' inability to get comfortable as a result of the pain and location of the PU to the sacrum, despite support surfaces in place. Within the residential site, carers noted that their relatives were most comfortable in the bed, both referring to how much their relatives loved their beds. Both also acknowledged that comfort played a contributing factor in pressure area care for their relative. As reported by these participants, comfort was promoted when issues were addressed pertaining to PU prevention such as repositioning through the use of pillows, not sitting out for long periods (relatives choice), and managing incontinence. One carer continued further to say that *"comfort is everything"* (Carer 8 Residential).

#### **4.6.2 SSKIN as a preventative tool**

As previously mentioned, there appeared to be limited knowledge and a lack of awareness among study participants of the existence of the SSKIN care bundle (Gibbons *et al.* 2006). However, as the interviews progressed and when pressure area care and the elements of the SSKIN care bundle (Gibbons *et al.* 2006) were broken down and discussed, the majority of study participants admitted to the SSKIN care bundle (Gibbons *et al.* 2006) as being a good idea and a useful and informative tool for preventing PUs. One carer states;

*"I think that the whole thing comes together nicely, you know"*

Carer 9 Residential

According to some participants, PUs were not something that they routinely thought about, thus revealing their preference to have been informed about pressure area care and the SSKIN care bundle (Gibbons *et al.* 2006) sooner, citing that others in similar circumstances would need to be told about it also. Noteworthy, what emerged from the data analysis was a recognition and expression of concern by several study participants within the acute and residential sites, for individuals in the community or indeed for those patients discharged home from hospital who lived alone. Emanating from these participant's perspectives was an understanding that people who lived alone would be restricted in their pressure area care. They were of the opinion that these individuals should be told more and educated on the dangers of PUs and preventative techniques that could be employed.

Whilst preliminary and early interviews identified confusion and a lack of awareness and knowledge reported by participants surrounding the SSKIN care bundle (Gibbons *et al.* 2006), it became important for this study that the writer gained an understanding of participants' perceptions of the core elements of PU prevention. Therefore it was deemed necessary by the writer to adapt the interview question scheduling accordingly in order to discuss and reinforce each element of SSKIN (Gibbons *et al.* 2006) thus allowing a rich in-depth discourse with participants. From the narratives, Skin inspection, Surface and Keep moving were illuminated by participants as the most important elements of the overall SSKIN care Bundle (Gibbons *et al.* 2006). The findings of the discussions of each component will now follow.

#### **4.6.2.1 Skin Inspection**

Skin inspection was identified by the majority of study participants as a key factor in pressure area care, many of whom considered it as primitive and potentially the most crucial step in PU prevention. A shared view among participant's indicated that skin inspection allowed for the early detection of PUs. One participant commented;

*"It's so easy to get them if they are not looked for and so unpredictable quick"*

Patient J Acute

*“Prevention is better than cure”* was a common concept among participants when discussing Skin Inspection. Furthermore, some participants remarked that early detection allowed for timely and proactive treatment if anything was spotted on inspection. However, diversity existed among study participants pertaining to the initial appearance of a PU as well as the location to where a PU could develop. In addition, there was disparity among the study participants as to how often a skin inspection should be performed. This ranged from *‘every couple of hours’* to *‘once a day’*, right up to *‘twice a week’*. Across the range of settings, some patients experienced a lack of control due to their condition or status which subsequently resulted in a reliance on staff to perform a skin inspection. Upon probing, patients reported that the frequency in which a skin inspection occurred varied. Some patients relayed that a skin inspection occurred regularly with one participant citing *‘all the time’* (Patient E Acute) In contrast, others remarked that a skin inspection was performed once a day, yet they did not consider or refer to a skin inspection occurring by staff when mentioning that they were repositioned potentially every one to two hours or when their hygiene needs were attended to.

Within the acute site it was acknowledged that there was a strong reliance on staff to perform a skin inspection due to patients’ post-operative status. However, it was reported by patients they couldn’t remember in the early stage of their post-operative period how often their pressure areas were assessed. As they became more alert they noticed a regular occurrence and reported that as they progressed in their recovery, the frequency of the skin inspections diminished. Patients reported that this was most notable in their transition from higher dependency units to the ward. However, some participants reflected that they were sometimes unaware of what tasks the nurses could be performing. The following quotation is an indication of this concept;

*“ Look, the nurses could be doing stuff that you wouldn’t see yourself you know, they could be checking so you know you just don’t know. They are probably doing it at the back of their head....”*

Patient K Acute



This sentiment resonates in other patients description of how nurses frequently removed the patients TED stockings and looked at their heels but that they didn't realise in the beginning what they were actually doing because it was not communicated to them. Within the residential and acute sites, some carers shared that they felt skin inspection should be performed more frequently, at the same time acknowledging that this may not always be possible. Some indicated also that they could and would like to be more involved in this element of pressure area care.

Participants within the PCA focus groups valued the skin inspection as one of, if not the most important aspect in PU prevention. They highlighted the support and education provided by the PHN on what to look out for and how to perform a skin inspection on their relatives' or the person they cared. They also relayed how, if they were concerned about an area of redness they would contact the PHN. This sentiment resonated also among the patients within the PCA, citing that they would contact the PHN should the need arise or if their carers alerted them to any areas of redness. Despite the presence of live-in or drop-in carers, the PHN was reported by most as reviewing their pressure areas during routine visits. Indeed this is well captured by one of the participants who humorously revealed;

*“ She (PHN) never comes here without having a, well she says to myself ‘don’t sit down I must see your bum’ (laughs)”..... “As a matter of fact I told her the last time, I told her I was going to start charging people for looking at my bum (laughs)”*

Patient M PCA

#### **4.6.2.2 Surface**

Some confusion existed among several participants when the topic of surface was broached, in that they believed the surface referred to the surface of the skin. Therefore clarification was given by the writer pertaining to its rightful meaning within the acronym SSKIN. The surface to which patients lay or sat on, was acknowledged by most study participants to play a dominant role in the prevention of PUs. This sentiment was more prominent in the residential site and PCA. Among this group of participants, there appeared a greater understanding of the

rationale and mechanics of any pressure relieving devices that were in their possession. This was primarily as a result of their condition or restricted mobility.

For many of the patients within this group, they associated the pressure relieving devices with comfort and reduced pain. In the residential site, seating was a priority for all patients most of whom referred to the uniqueness of their own customised seating and/or cushions, which some acknowledged, contributed to the prevention of PUs. This was supported by the carers within this site also. Many of these patients were affiliated with the O.T.s and most identified the importance of contacting them pertaining to their seating, positioning and pressure relieving equipment among other things. The following quotations are a representation of this concept;

*“ Well they are very good about cushions on the wheelchair. They can be very uncomfortable on this power chair. (pause) And the Occupational Therapist got it fixed and it improved.”*

Patient C Residential

*“Because he’s an Occupational Therapist he would be a good man to keep in with too, eh, cause if you need any adaptations done they are good for doing that you know....”*

Patient O Residential

The OT was, or had been, involved to some extent with some patients within the PCA. However as discussed previously, some patients took control and decided to adapt their home and acquire medical devices and pressure relieving equipment in preparation for an eventual decline in their condition. All of the patients in the PCA had a pressure relieving cushion and used it in their day to day activities suggesting that this significantly contributed in the prevention of PUs.

It was acknowledged that the PHN was the linchpin between therapy staff, in acquiring any further equipment. This sentiment echoes among the carers within the PCA. Within the acute site, minimal reference was made pertaining to the presence of an OT among patients care, with study participant’s citing that they

believed it was the nurses that decided on the presence of any pressure relieving devices. The presence of any pressure relieving cushions was not evident within the patient narratives. Also from the narratives in the acute site, almost all of the patients (all but one) were nursed in the old style hospital beds (on the ward) that had to be manually adjusted if they so wished to sit up or lie down, thus relying on staff and limiting their self involvement in pressure area care. This quotation highlights one such patients' experience.

*"But I'd say the beds could be, well the one I was on should be thrown out. That's my opinion 'Cause as I say you have to lift it up and pull it out and then put the pillows behind it. There is no control over it, there's no, not unless the way it is until the nurse comes and takes the pillows away and puts the bar done, so they should be done away with. That's my opinion."*

Patient J Acute

The same patient then professed that it was because of this bed that they got up and mobilised quicker. Notably, some of these same patients did have a pressure redistribution mattress in place with one patient highlighting that as soon as you got the mattress, you realised and felt the benefits of it straight away. Within the focus group in the acute site, one carer expresses their belief that the alternating mattress had saved their relatives life while another refers to it as the '*maximum bed*' (Carer 7 Acute ). However the third family member thinks that this mattress caused their relative some discomfort as she could be too far sideways, therefore believing that she requires more observation while in bed.

Across the three sites when discussing the surface with carers a sense of curiosity emerged among most pertaining to the comfort and feel of the mattress. In the PCA they also made reference to how the electronic hospital beds assisted them as primary caregivers in manual handling techniques and indeed care of their own backs. Overall, appraisal and appreciation was proclaimed by all careers in both the residential site and the PCA regarding the pressure relieving equipment and/or electronic beds that were provided to their relative or person they cared for. While some expressed that the hospital bed was one of the many things contributing to

PU prevention, others articulated how they firmly believed that this was the main contributing factor in PU prevention. This is reflected in the following quotations;

*"I do believe the bed \*\*\*(spouse) is in, that type of bed is the main reason that \*\*\*\*\* hasn't got them. I firmly believe that you know"*

Carer 9 Residential

*"I must say, when my \*\*\*\*\* (spouse) was bedridden, it was (the hospital bed) probably the greatest preventative factor."*

Carer 1 PCA

Further data analysis revealed how multiple study participants, addressed how elements such as sheets, rolled up clothing, underwear, rough textures, crumbs in the bed and the presence of devices whether medical (for example, drains/tubes) or personal (for example, mobile phone/brush) all played a role in PU development thus citing the need to monitor the surface to which patients lie or sit on for any of these, to aid prevention.

Significant emphasis was placed on the use of pillows as vital components in PU prevention yet several patients emphasised how sometimes it was hard to get them positioned right. Across the range of settings, many participants whether a patient or carer, communicated how pillows were used to offload feet, heels and elbows. One carer described how pillows are positioned in protecting his relatives' feet and heels in that they would be *"in a kind of empty space"* (Carer 9 Residential). Some patients described and reflected on how pillows helped relieved the 'pressure' they experienced. The following quotation gives an in-depth glimpse of one such experience;

*"...everything is just about trying to take the pressure off you, do you know what I mean? Because it is so uncomfortable like you know. I don't think people that haven't been through it realise, how uncomfortable it can be, like you know. It nearly, it would bring you to tears. So just to have someone that can or knows how to position your pillows or how to sit you up properly, just simple things like that do you know what I mean, it makes*

*a world of difference.”..... “When the nurse came round here at night I’d just say, just help me up and just shuffle the pillows and change them around. You know I would lie back down and I would be comfortable even for a just a few minutes like.”*

Patient I Acute

#### **4.6.2.3 Keep Moving**

When discussing the ‘Keep Moving’ component of the SSKIN care bundle (Gibbons *et al.* 2006), participants acknowledged mobility as one of the pivotal factors in preventing PUs. Many signalled mobility to be on a par with Skin Inspection in PU prevention, if not higher. In fact, when reviewing the narratives, mobility and repositioning were the most common references cited throughout by study participants. In addition, within the narratives, the most detailed and lengthy discussions pertaining to SSKIN (Gibbons *et al.* 2006) and PU prevention were centralised around mobility and repositioning. As one carer acknowledged when it comes to PU prevention *“mobility is everything.”* (Carer 8 Residential).

For those patients that took part in this study their level of mobility varied across the range of settings. Indeed the writer has reflected within her journal how mobility was noted to be unique to each patient involved. Once again, data analysis revealed how those participants who had increased awareness or previous personal/employment experiences of PUs displayed a greater understanding of the role that mobility played in PU prevention. This was evident among patients who had previous experiences of a PU(s) to their heel(s). It was predominantly this patient group that spoke of friction and shear as contributing factors in PU development. Here it was accentuated how to *‘offload’* or *‘relieve’* the pressure on their heels by lifting them up onto pillows and to take due care in positioning them with a clear avoidance of any friction on movement.

Patient participants who had a form of paralysis or had limited or restricted mobility, indicated that repositioning played a fundamental role in the prevention of PUs, with many identifying that this helped *‘take the pressure off’*. This was most prominent and recognised more so among participants in the residential site. Here,

the majority made reference to and described how repositioning occurred during their day, examples of which include; they were turned regularly, assisted to be repositioned in the chair, limbs checked, manoeuvred and repositioned, transferred at intervals from bed to chair (and vice versa), using the hoist to enable a change and relief in pressure. This was also alluded to among carers within this site as they relayed how they have witnessed a gradual decline in their relative's condition over the years.

Of note, patients reported the absence of a Physiotherapist within the unit. The reliance that patients had on staff for performing repositioning activities was evident. However it was reported by most that many of the re-positioning techniques employed were at the request and preference of the patient thereby highlighting their involvement in care by controlling their requests. One patient within this site, who displayed a difficulty in maintaining a focus on the direction of the questions during the interview process, did however acknowledge several times how repositioning and being turned regularly by staff aided them in avoiding the occurrence of a PU. Another identifies how;

*“you shouldn't be sitting on a chair for too long because the pressure will only get sore”*

Patient D Residential

These sentiments resonate among other participants within this patient group as illustrated in the following excerpt;

*“ The main way is to get it off. Take the pressure off. Take the pressure off it. Em, you can't really do that when you're sitting up and you can't, I mean lying on your back, you can't do that either. So you have to be or if it was say if it was on my side, it would be have to be back to my side, back to my side.”*

Patient A Residential

For the majority within this participant population despite their restricted mobility, this did not inhibit or deter their ability to maintain independence. The electronic

controls that were uniquely customised on their motorised wheelchairs allowed them to take control and independently manoeuvre the wheelchair to their desired destination thus giving them ability and freedom to live a comprehensive lifestyle. This was indeed reflected upon and noted in the writer's journal, especially at the recruitment phase when many patient participants were recurrently on day excursions.

Discussions on 'Keep Moving' in the acute site unearthed how for some participants their initial thought process naturally associated early mobility with the need to return to normality and be able to walk independently on discharge home. However for some patients, their inpatient experiences broadened their perception of mobility to expand its function as an important role in the preventing PUs. One participant expressed how mobility is;

*".....key to the avoidance of things going wrong"*

Patient N Acute

In the initial post-operative stages, it was discussed by all patients how they relied heavily on staff to reposition them in bed and to assist them with their mobility. However as previously mentioned, some reflected how in their recovery, it was never explained to them as to why repositioning was necessary. Many felt that any communication pertaining to mobility or indeed about PU prevention came at a later stage in the trajectory of care. This communication reportedly came mostly from nurses. Although all patients were linked with the physiotherapist, there were mixed reports from patients to the extent of the information given to them by the physiotherapist about PU prevention however, they acknowledged that the physiotherapist played a key role in getting them out of bed and placed emphasis on the necessity to mobilise around the ward. Be that as it may, some patients conceded how tiredness negatively impacted on their want and ability to mobilise. Others described how you needed to be in the right frame of mind and motivated to mobilise, as distinguished in the following quotation;

*" Well if people can get up and get moving and walking as soon as possible, I think it is so beneficial to people. I know you can say I'm sore, I can't get*

*out of the bed and all that, but I think your mental attitude has to be right to say get up, just do it."*

Patient I Acute

Many patients reported how in the early stages they had to constantly move or be repositioned regularly by staff to promote comfort, with some describing how they *'got stuck in the one position'*. In particular 3 patients reported that they needed to be repositioned as frequent as every 15 minutes maybe even more. As patients progressed in their recovery, it was acknowledged that their reliance on staff diminished. The presence of a stoma, a post-operative wound and any medical devices were significant contributing factors listed by patients in limiting and restricting their movement. It was acknowledged by all that when the medical devices were removed they were able to mobilise more freely. The following patients experience reflects this;

*"....They took the epidural, they slowed it and slowed it and then took it off and then the next thing they took the urine bag off the day after which was great.....I wanted to get meself clean. I wanted to wash, I wanted to go into the bathroom and when they took it away I went for it"*

Patient J Acute

In her reflective journal, the writer noted from the time that she met patients in the preliminary meetings of the recruitment phase to her return to perform the interviews, she remarked on the detachment of medical devices previously witnessed, the change in the physical appearance of patients and their increase in mobility. Data analysis also highlighted that mobility appears to be the most prominent and frequent preventative measure communicated to patients by staff within the acute site.

Upon reflection of their experiences, carers within the acute site identified movement as a key factor in the prevention of PUs and relayed how, if they had known more about PUs in the early stage of their relatives' recovery from the surgery, they would have done more to encourage mobility to aid in prevention. Great emphasis was placed by these carers on the need for their relative to



remain in bed and be repositioned and turned frequently to aid in an attempt to heal the PUs that their relative had developed. They believed that the alternating mattress and specialised bed that she was on was assisting with this. They disclosed how the physiotherapist had educated them on how to offload their relatives' heels and that they found this very beneficial. However they followed on to say that there was now limited physiotherapist involvement in their relatives care. They portrayed a sense of dissatisfaction with this as they strongly felt that continued leg and arm exercises were necessary, with the frequency of this increasing, to maintain muscle tone as they hoped that their relative would be able to mobilise again in the future.

Carers in the PCA also deemed repositioning and mobility of their relative/person they cared for as a crucial contributing factor in the avoidance of a PU. Their experiences of being the primary carer influenced their decision making on this topic. They conceded that it was also as a result of the communication and education by the PHN that contributed to their realisation of this. There was a variety of creative techniques adopted by these FOCUS GROUP members to encourage mobility and repositioning with their relatives or person they cared for. The following quotations depict this concept;

*"Sometimes I tell my woman to go marching. Can you kick my leg? Now the other. Any movement that they are, they feel happy as if they are playing with you at the same time. Yeah. So if your woman is sitting and you are not talking to them they just keep on sitting down for a couple of hours. For me, I really talk with them."*

Carer 4 PCA

*"Well because my \*\*\*\*\*(relative) is not bedridden, I would prompt her every 30 minutes to get up and walk around and whenever she has the carers in. Em and at night time, when she had the pressure sore on her back, to remind her to sleep on her sides"..... "She never moves so you know I have to remind her. I have left a big note beside the bed 'remember to sleep on your side'"*

Carer 3 PCA

This creativity extends further into the patient group in the PCA. One participant narrated how he uses his seated buggy to aid movement in the prevention of PUs;

*“I use em, my buggy, I go out for a drive in that and that shakes my buttocks quite a bit and that seems to be very good because on a rough road it’s not very, well there is no hydraulic springs on it so you can feel the bumps”*

Patient M PCA

Patient participants within the PCA share common attributes when discussing mobility in the prevention of PUs. For all of these patients in the PCA they reported on their collection of walking aids with some only utilising these aids when necessary. Whilst many attributed mobility and repositioning as key contributing factors in the prevention of PUs, others intensified their belief in its use by associating it with the idiom *‘prevention is better than cure’*. All agreed that repositioning is a fundamental aspect to their care, many of whom citing it as a frequent task they perform to relieve the *‘pressure’* especially when sitting. One patient delineated how it was not easy to sit in a chair all day thus signalling her need to *‘shuffle’* in the chair. Others expressed how they never sat for very long as the discomfort they experienced would be enough to make them move.

For one patient in particular, the fear of getting a PU acted as a stimulus for her mobility to prevent PUs. In contrast tiredness and mental attitude negatively impacted on some patients want to mobilise but in the same vein it was acknowledged that mobilising was a necessity. This was similar to the experiences conveyed by some patients in the acute site. As reported by patients within the PCA, the community physiotherapist was linked in with 2 patients, but had previously been involved with others. Patients recalled how the physiotherapist had, when giving exercises, discussed repositioning and made reference to PU prevention. However it was the PHN who was most commonly referred to by participants who communicated the importance of mobilising and repositioning to prevent PUs. No reference was made by the focus group members to community physiotherapist involvement.

#### 4.6.2.4 Incontinence

Stemming from the participants narratives, there existed a lesser understanding and somewhat subordinate emphasis among participants pertaining to the role of incontinence in PU prevention. It must be pointed out that, as reported by participants, only a minority of patients within this study experienced incontinence some of whom made little, if any, reference to it in the interview process despite probing by the writer. This was a stark contrast from the writer's initial meetings with these participants in the recruitment phase of the study. Within the writer's reflective journal it was noted how these patients spoke of their issues with incontinence and how they managed it. This was not reflected or captured to the same extent within the narratives.

When discussing the Incontinence element of the SSKIN care bundle (Gibbons *et al.* 2006) with participants, a minority addressed the presence of acidity in the urine and faecal matter on the skin to be contributing factors in damaging the skin. Two participants who did reveal knowledge of this, perceived that it would burn into the skin and could cause major problems, particularly if the skin was anyway tender. However, most participants portrayed a sense of uncertainty to its role in PU development but acknowledged that it would be a contributing factor. When discussing this topic in relation to PU prevention, one carer voiced her opinions;

*"I can imagine that it would be a disaster waiting to happen if somebody was incontinent"*

Carer 8 Residential

Further reflection on the topic among some participants resulted in a recognition that management of incontinence would be an important part in preventing PU, with emphasis directed towards keeping the skin dry. Hygiene was reported as the necessary means in which to keep the skin clean and dry thus aiding in the prevention of PUs.

From the writer's reflective journal, some participants revealed in the preliminary meetings that they were incontinent of urine. Yet, during the interview process many did not allude to their state of continence despite probing by the writer.

Those participants who reported episodes of incontinence were primarily located within the residential site. One patient acknowledged that they had many risk factors which made them at risk of a PU. They listed incontinence as one of these factors and reported that they relied on the staff to assist with hygiene needs. Another patient in this site, despite previous discussions, did not allude to any issue with incontinence during the interview process. Yet the importance of hygiene and washing correctly was referred to repeatedly.

Many of the patients within the acute site divulged that they had a catheter in place after surgery some of whom found it most uncomfortable and inhibited their ability to mobilise. Although most patients within this site reported no difficulty with incontinence issues, one participant shared their experience of their pre-operative condition;

*"I had that thing out of me as well, the faecal stuff, you know that. Em, so now they were great at cleaning it up. I was embarrassed about it you know that kind of a way. Embarrassed like, 32 years of age and I'm soiling the bed. But it wasn't my fault like you know. But eh, they cleaned me up and washed me and all that kind of thing, me behind, before they let me back in"*

Patient K Acute

Perspiration on the skin was revealed by some as a contributing factor in the development of PUs as they associated this with excoriation of the skin. In particular one patient disclosed how they found this difficult to deal with, as they had no control over it, but commented;

*"the nurses were on top of their game as regards changing the sheets and stuff like that, to make sure that you were always dry."*

Patient F Acute.

This same patient alluded to feeling heat rising in their heels in association with perspiration which were only relieved when their heels were offloaded and cooling measures were applied.

Hygiene and the use of creams were listed by many as the fundamental way in managing incontinence. The majority of participants within the study conveyed how, they felt by looking after your skin through hygiene and the use of creams (moisturisers, barrier and emollients) this would help in preventing PUs from occurring. In fact many participants identified this as part of their role in PU prevention. When discussing this concept, some participants voiced how important it is to look after the skin. The following quotation captures this idea;

*“You know the skin is awful important. It’s yours and it’s the only one you have got. So you need to look after all the parts, even the parts that’s not on show”*

Patient J Acute

#### **4.6.2.5 Nutrition**

As identified within the narratives, the conversation that surrounded the nutritional component of the SSKIN paved the way for varying concepts and ideas among participants pertaining to PU prevention. The role of nutrition in the prevention of PUs appeared to have a lesser prominence, nonetheless, nutrition was described by many to be an important contributing factor in PU prevention, yet many were unaware as to what extent its role played. A minority mentioned the nutritional value of protein. For the most part, participants considered nutrition to be a core attribute in the ability to perform routine daily functions. The following is an indication of that perception;

*“Yeah I mean it prevents everything, doesn’t it? Nutrition and hydration. It’s good for everything.”*

Carer 8 Residential

However it is also recognised that;

*“.....diet of course is of course another thing you think you should know too, but you don’t really”*

Patient A Residential

One carer who initially believed that PUs could not be prevented, attempted to link nutrition with PU development as the following excerpt portrays;

*“....but when you go back to the pressure sores and you think right, ok, those components are nutrition, pressure and mobility. So if you look at it you are going to have no mobility if the person doesn’t have the energy to do the physiotherapy. So because me \*\*\*\*\* (family member) wasn’t eating, that had to be definitely impacting on how she was performing down in the gym with \*\*\*\*\* (physiotherapist). It had to have been”*

Carer 7 Acute

Among the carers there appeared to be a greater emphasis on the role of nutrition in caring for their relative/person they cared for, many of whom assisted at meal times and brought in food or drinks preferred by their relative. They reported also on the benefits of drinking fluids in sustaining hydration of the skin but also to aid in the overall care of their relative/person they cared for. Some study participants also commented on how they believed nutritional support drinks were important.

Across the range of sites, there existed a sense of apathy among some patients, as they reported that they sometimes found it difficult to eat and eat well, citing age and lack of motivation as contributing factors. The presence of a live-in carer to cook meals or the availability of the meals on wheels service assisted in compressing this notion. Patients who were located in the acute site reported limited input into their nutritional and dietary status in their post-operative recovery as they received their nutritional supports via Intravenous Total Parental Nutrition (TPN). Interestingly, despite all patients reporting that the dietician was linked in their care, none could recall if they had received any information about pressure area care from this source. This was in contrast to the residential site where all patients reported easy access to the dietician who, they reported, at some point relayed some form of information to them about pressure area care. However, more patients identified a general liaison with nutrition in their overall care.

When discussing nutrition one subject that emerged from some of the narratives related to weight as a contributing factor in PU development. For those who

discussed this, there were mixed opinions on how weight played a role in PU development. The writer has noted within her journal similarities in patients' actual weight and their perception of how what type of weight assists in the development of a PU. When discussing PU prevention, one patient commented on his weight as a contributing fact as shown in the following quotation;

*"Eating regularly and not being so obese, because I am quite obese. Yes I'm sure it contributes. I don't think it, I know it."*

Patient B Residential

Another patient recalled how she previously thought it was better for her to be thinner and lighter in weight as this allowed for her easy transfer from car to chair by family members, at a time when hoists and wheelchair accessible cars were not available. However her perception of this changed, following her experience of developing a PU and the effects that followed. Another participant voiced a similar opinion;

*"But I am much thinner than I was you see, so that's a problem you know? I am just skin and bone really. I have very little, well my muscle has gone considerably and my fatty tissue has disappeared altogether almost. Lots of people would envy me, but I don't!"*

Patient P PCA

#### **4.7 'Communication is Key'**

For the purposes of this study, 'Communication is Key' conveys the study participants' beliefs on the important role that communication, both verbal and/or written, can play in pressure area care and PU prevention. The findings documented within previous themes of this chapter lend support to the composition of this keynote topic. From the outset, a clear example of the lack of knowledge and awareness illustrated by participants surrounding the SSKIN care bundle (Gibbons *et al.* 2006) in the prevention of PUs and the existence of the Pressure Ulcers to Zero (HSE 2013a) collaborative resulted from a dearth in communication. Data analysis revealed that all study participants made some reference to how communication played a role in PU prevention. Education &

information giving and feedback from staff were two sub-themes that emerged from the narratives which underpin the formulation of the main theme, communication. One participant's staunch beliefs pertaining to the value communication played in PU prevention, gave rise to the title of this section;

*"Communication is key"*

Patient N Acute

#### **4.7.1 Education and Information Giving**

Disparity among participants was noted within a multitude of concepts pertaining to pressure area care and PU prevention. This stemmed from the different levels of knowledge evident within the group of study participants. From the writer's journal and indeed as evidenced within some of the narratives, some participants sought further information and education regarding PUs and preventative measures during the interview process with the writer. Those individuals who had previous past personal/employment experiences of PUs, displayed a greater awareness, understanding and knowledge base associated with the avoidance, development, and effects that PUs could have on individuals, thus leading to increased involvement in their own pressure area care. Carers within the PCA displayed cognisance of the importance of providing pressure area care for their relative/person they cared for. In a similar vein they acknowledged that it was communicated through information (verbal & written) and education given by the PHN and the HCA associated with the primary care centre that their awareness of pressure area care and PU prevention techniques came about. In fact one carer remarked;

*"But is it not a factor of the person who is giving the advice and the support? You know, I'd say to myself how I would have known about it unless I was told it and unless it was pointed out to me. Maybe I would be on the internet and reading up, but it's not the same thing as getting first hand guidance and advice. And assisting in the inspection and becoming aware of it that way."*

Carer 2 PCA



Nearly all of the participants in the PCA rendered acknowledgement of the support, guidance, advice and education given to them about different aspects of PU prevention by the PHN and the HCA within the primary care centre. The following quotation is an indication of that conception;

*“I’d actually say that maybe we were, those of us who live in this community are probably fortunate first of all that \*\*\*\*\* (named PCA) was part of an experiment programme and I gather that from the nurse and indeed her assistant that they were doing training in it and there was awareness and they were passing on that awareness. Certainly they were passing it on to me”*

Carer 1 PCA

Listening to staff and co-operating with their instructions, were listed by some participants as an important aspect of PU prevention. On the other hand, others relayed how staff also shared in the co-operation with participants and listened to their concerns and needs pertaining to pressure area care. One participant referred to this as a ‘2 way street’ (Patient N Acute)

Communication was an important facet for carers within the acute site. They experienced that the informational issues about the extent of the PU their relative had, came quite late. Also, they stressed how they would have liked to have been educated and told more about pressure area care sooner, as they felt this would have resulted in them playing a larger role in the prevention of their relative developing a PU. They also expressed how information provided to them about the PU staging system, helped them to understand the extent of the PU their relative had. Noteworthy, within the writer’s journal, the development of their relatives PUs did not occur in the acute site setting of this study.

There were mixed opinions among other study participants about the amount of advice, information and education provided to them by staff pertaining to pressure area care and PU prevention. Of note, information and education from other disciplines were more prominent within the residential and acute sites. This however may be within a general capacity and not related directly to pressure area

care or PU prevention. A general consensus among all sites hailed the nurse as the primary informer. Nevertheless, some disclosed that they received no verbal information from staff, while others reported how mobility was the most prominent feature of PU prevention alluded to by staff. In contrast, one participant in the acute site who showed a good knowledge base on PU prevention, citing *'friction'* and *'shear'* as key contributing factors in PU development, also alluded to the extent of communication that occurred with staff as the following illustrates;

*" They made me very aware of it now (laughs). They were tormenting me to put my feet up all the time"*

Patient E Acute

It was pointed out however that when it comes to education, you would want to be *"in a mood to understand"* (Patient K Acute). Whilst other members in the acute site, reported that in the initial post-operative stages, they experienced an inability to absorb any information that was relayed to them. When participants in the acute site were asked as to when they would have found it most beneficial to be informed of PU prevention and the SSKIN care bundle (Gibbons *et al.* 2006), most felt that it would be most pertinent on admission to the ward, while one participant in particular felt a nursing assessment of the patient would decide on this as the following quotation indicates;

*"For me, I think communication is the most important thing and I think when amongst the nursing group, for want of a better way of describing it, is eh, satisfied that the patient can comprehend eh, that the communication should start then."*

Patient N Acute

Some difficulties regarding communication cited among participants included a comment by one carer where it was identified how the language barrier between some foreign staff inhibited both the carer and relatives understanding and ability to follow directives. Another participant reported how medical staff may use different terminology when discussing PUs, thus inhibiting a patients' level of understanding.

*“People would have like, there are certain ways that the doctors would say things that you wouldn’t understand as opposed to how another doctor would”..... “then they would probably use a different name for them you know. They would use a lot more technical words than I am using here you know”*

Patient O Residential

A resounding theme to emerge from the narratives was the need to inform and educate people on the importance of pressure area care and indeed PU prevention, with many acknowledging the SSKIN care bundle (Gibbons *et al.* 2006) as a valuable tool for doing so. The use of visual aids and information leaflets pertaining to pressure area care and the SSKIN care bundle (Gibbons *et al.* 2006) in PU prevention, received positive responses among participants as an effective means of communication but only as part of the package. As alluded to in the Awareness section of this chapter, participants were forthcoming with their own ideas on communication methods to inform individuals of the SSKIN care bundle (Gibbons *et al.* 2006). Verbally communicating with individuals was listed as the most effective way to promote it.

#### **4.7.2 Feedback**

Many participants indicated their desire to receive feedback from staff relating to elements of their pressure area care, most notably pertaining to Skin Inspection. As indicated by many patients, a strong reliance existed on staff for this activity due to their inability to review areas of their body themselves. Consequently, it was aspired by some that they receive feedback from staff as to the condition of their skin. One patient highlighted how feedback could help individuals who are prone to PUs as illustrated in the following quotation;

*“Maybe feedback to people prone on how their skin is. You know your skin is looking very well or your skin is a bit red and tell them a little bit how they might improve that, so that they feel involved”*

Patient C Residential

Some patients reported that they did receive feedback from staff about their pressure areas, whilst others reported this occurred as a result of their choice and decision to ask. Either way, this feedback subsequently resulted in their involvement in the decision making process pertaining to management of their pressure areas.

One of the carers in the acute site reported how more feedback from staff would be most beneficial to them as a family unit, especially in the progression or decline of their relatives PU wound; as she felt it would keep them more informed. In contrast, carers within the residential site relayed that the staff give regular accounts and feedback of their relatives pressure area care. Some of the carers within the PCA relayed how, as part of the feedback relating to skin inspection given by the PHN or HCA affiliated with the primary care centre, they were shown and advised on the most appropriate course of treatment necessary, of which they found this very beneficial.

It was interesting to note how some participants suggested that an awareness campaign should be commenced on PUs, similar to that of the smoking campaign. One participant's comments highlighted how feedback to all patients and carers on the results achieved from the Pressure Ulcers to Zero (HSE 2013a) collaborative would enhance the emphasis and promote awareness. This is well captured in the following excerpt;

*"I think feedback as well. When you started to talk to me I couldn't really see where the conversation was going, but the minute you said it has gone from 50% to 73% I was like a light bulb then. I said Jazus, you can do something about these, so for other people into the future. All these things are preventable like. They are so serious and that you can actually prevent them?"*

Carer 7 Acute

## **4.8 Resources in Prevention**

In the context of this study, this theme, Resources in Prevention, portrays the perceptions of the study participants in what they believe to be important components in PU prevention. The overarching concept of this theme stems from study participants attention to detail in their surroundings. From the narratives, participants communicated how they observed and witnessed some influencing factors that they perceived to be fundamental in pressure area care and indeed PU prevention. 3 key concepts were identified in the narratives that lend support to the overall theme. These concepts include

1. Lack of staff availability
2. Lack of resources
3. Knowledge and restrictions among carers

It is important to acknowledge, that whilst almost all study participants spoke of resources and the prominent role they may play in PU prevention, there was no great elaboration on this topic from some members of the group. However the focus group in the PCA is an exception as much attention was drawn to the topic of the 'agency' HCA's.

### **4.8.1 Lack of Staff Availability**

Many participants reported how they believed there to be a significant dearth of nursing staff available. This was reflected more so from the participants within the acute and residential sites. However some participants in the PCA also reflected on previous hospital experiences and reported similar findings. Despite most participants attributing acclamation and praise towards the nursing staff and to the work that they do, some conceded that at times staff could not meet or fulfil the needs attributed to activities pertaining to pressure area care, thus identifying an increased risk in the potential occurrence of a PU. This, they felt was as a result of a lack of staff availability and increased workload. The following quotations reflect this sentiment;

*“And then I have to say flipping the coin then on the other side, there are so many patients here and there is only so many nurses, it can happen. You know that you could come in and forget and come back out and it could go out of your mind, you know what I mean? To be fair to the staff”*

Carer 5 Acute

*“I think regular showers are the most important thing. But it’s not easy when you are short staffed to do a daily shower so.”*

Carer 8 Residential

#### **4.8.2 Lack of Resources**

Some participants commented on the lack of resources made available to them. This was most notable within the acute site when patients spoke about the support surfaces. Many of these patients expressed how they felt an electronic bed would have been more beneficial and comfortable to them in the recovery stages of their post-operative period. Indeed, they postulated how this would have contributed to their self involvement in repositioning and it would have allowed for the relief of pressure. For some, they had the experience of the electronic bed in the higher dependency units. It stands to reason why these patients then stressed that the ‘old style’ beds should be made obsolete. In a similar vein, when discussing the use of pillows and cushions as supports in pressure relief, many seemed unaware of the existence of any such thing. Within the narratives, one patient in particular extended his frustration about not being offered one as he felt this would have made an impact in assisting in pressure relief to his sacrum. Indeed this participant asked the writer to report this back to the Clinical Nurse Manager.

#### **4.8.3 Knowledge and Restrictions among Carers**

This concept originates within the narratives from the focus group in the PCA. An area of concern portrayed by carers within this group surrounded the role of ‘agency’ HCAs that were employed within the health service to assist carers in the needs of their relatives. A lengthy discussion was had by carers of which, as noted in the writer’s journal, continued when the focus group session had ended. One carer reported how she found significant differences in the level of care provided and knowledge between the ‘agency’ HCAs and the HCA affiliated with the

primary care centre. Another carer conveyed her perception as illustrated in the following excerpt;

*“Going back to the carers, well I think they need more education and more flexibility so that they can do more things for the clients and for the families, like I had to be proactive the whole time.....”*

Carer 1 PCA

Confusion existed among carers on the extent of the scope of practice of the ‘agency’ HCAs. For one carer she conveyed her frustration when, as reported by some of these ‘agency’ HCAs, that it was not in their remit to change a simple preventative dressing on her relatives back, (which had no wound under it) following a shower that they had given, thus leaving a wet dressing on her relatives back until the family member returned home. Another carer reported that she had to remain proactive throughout. Indeed the carers relayed how they felt that it would be necessary for these ‘agency’ HCAs to be educated further in PU prevention as they felt they had very limited knowledge. They also cited more flexibility within their job role as an important aspect.

#### **4.9 Conclusion**

The findings within this chapter have captured many diverse concepts, ideas and perceptions from each study participant pertaining to their experiences and involvement in PU prevention, the SSKIN care bundle (Gibbons *et al.* 2006) and the Pressure Ulcers to Zero quality improvement collaborative (HSE 2013a). Overall 6 main themes and their subthemes were presented. These themes included;

1. Awareness
2. Patient Involvement
3. Family/Carer Involvement
4. Prevention is Better than Cure
5. Communication is key
6. Responsibility.

# **Chapter 5**

## **Discussion of Findings**



## **5.1 Introduction**

This chapter will discuss the key findings from the research exploring the patient and family/carer experience of implementing the PU prevention care bundle, known as SSKIN, within a regional quality improvement collaborative. The research findings will be discussed in the context of existing literature. The chapter has been broken up into 3 sections; Participation & Involvement, Health Promotion and Prevention is Better than Cure. Finally the chapter will close with a summary of the salient points.

## **5.2 Participation & Involvement**

### **5.2.1 Collaborative Involvement**

The findings of this study demonstrated that the majority of participants across the range of settings displayed a general lack of awareness and knowledge pertaining to the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative. Additionally, only a minimal number of participants accredited an existence of the SSKIN care bundle (Gibbons *et al.* 2006). However, the latter may be attributed to the different collaborative techniques adopted in each setting pertaining to PU prevention. For example in the PCA they used the acronym PROMPT (See Appendix 16), while in the residential site, although each core element of SSKIN was incorporated into individual patient care plans, it was not promoted as a SSKIN. Be that as it may, many study participants in each area displayed limited awareness on pressure area care or PU prevention techniques.

With widespread enthusiasm and support in the literature for patient and family involvement in health care planning and service development (Bate & Robert 2006, Andersson & Olheden 2012, Vaismoradi *et al.* 2014, Groene *et al.* 2014), these findings are therefore the most salient and yet surprising. The findings were unanticipated because, as one of the core attributes of the initiative, it was envisaged that a patient and carer centred approach be adopted by collaborative teams to improve healthcare methods in relation to PU prevention. The literature highlights how a quality improvement approach based on the idea of collaboratives (Overtveit *et al.* 2002), involves patients working interdependently with professionals to assist in delivering improvement (Renedo & Marston 2015). Also, it is suggested that failure to utilise patients' perspectives in the development of

new measures may pose a threat to the content validity and responsiveness to change, as outcomes relevant to patients may not be included (Gorecki *et al.* 2009). Yet this rhetoric of engaging patients and carers in the collaborative process does not appear to be a reality in practice. This is evidenced from the findings in this study, with only 4 people yielding some cognisance of the Pressure Ulcers to Zero (HSE 2013a) collaborative, 2 of whom reportedly took part in collaborative activities, i.e. the group work video and feedback on a poster.

While engaging health care professionals in a quality improvement initiative is crucial for its success (IHI 2003), there needs to be a shift in focus to include patients and carers. The WHO (2015) advocates that patients and carers perspectives are a central reference point in shaping the safe and high-quality delivery of health services, including health service decision making. Indeed Renedo & Marston (2015) contend that without understanding patients' perceptions on quality improvement interventions there lies an inherent risk that policies and interventions will be disproportionately orientated towards service providers and disconnected from patient realities. This means that for future collaborative success, greater emphasis needs to be placed on creating awareness among patients and carers as well as health care professionals in the initial collaborative set up in each site.

The HSE clearly indicates in the Corporate Plan for 2015-2017 (HSE 2015a), that part of the main focus is to incorporate patient experiences and strengthen the patient's role in the improvement of care quality. In line with this, is an aspiration of enhanced engagement with patients and their carers and their involvement in the design and delivery of services (HSE 2015a). Heralding this concept, is one of the most striking statements to capture the writers attention from the literature, *"If health is on the table, then the patient and family must be at the table, every table, now"* (Leape *et al.* 2009; 426). Adopting this statement for future collaborative efforts, could assist in generating more staff awareness on the importance of patients and carers in service design and their subsequent involvement in PU prevention strategies.

Participants displayed a desire to receive more information and be more involved in the collaborative process and in PU prevention using the SSKIN care bundle (Gibbons *et al.* 2006). This was indeed evident from the positive reactions, discussions and interest portrayed by many participants upon receipt of information given by the writer of the site or care areas' participation in a quality improvement collaborative. Moreover, the overall success of the Pressure Ulcers to Zero (HSE 2013a) collaborative results for example, the reduction in the incidence of PUs by 73%, was received with profound enthusiasm. Therefore, it seems only logical that providing patients and carers in each setting with such basic yet valuable information could result in heightened awareness and elicit their willingness to engage, learn and become more proactive in participation in the collaborative process. In addition, it could also encourage patients and carers to become involved in shared decision-making and self-care practices pertaining to PU prevention. This has substantial meaning for future collaborative efforts. If an overall reduction of 73% in the incidence of PUs can be accomplished with minimal patient and carer involvement, a greater reduction could be achieved if patients and carers are fully informed and included in care practices and overall collaborative strategies.

Weingart *et al.* (2011) proposes that patient and carers are an unaccounted source of strength and resilience in health care. This sentiment resonates in the study findings whereby patients and carers offered valuable ideas as to how awareness of the Pressure Ulcer to Zero (HSE 2013a) collaborative could be promoted. Additionally, they offered different views on how to actively engage patients in their own pressure area care. However, other than one participant partaking in the group work video, with another commenting on feedback given to a poster (both of which occurred in the residential site), no other participants active participation or feedback was sought in the live collaborative process. Participants in the PCA who acknowledged some cognisance of the Pressure Ulcers to Zero (HSE 2013a) collaborative, was through staff communication of their participation in a new initiative and that they were attending training days, but no offering was made to include or seek engagement from these participants as reflected within the narratives.

From the writer's reflective journal, it was noted that staff in the acute site informed the writer that they had sought feedback from patients regarding the poster design and location, yet this was not reflected in the interviews. This was inclusive of the one participant who was an inpatient for an extended period during the active collaborative phase. Be that as it may, for the majority of those participants in the P.C.A., not all participants were known to the PHN at the time of the active phase of the collaborative, nor were any patients' or carers, bar one, affiliated with the acute site at the time of the active collaborative phase in 2014. Subsequently, the time lapse that has occurred from the initial implementation efforts and active stages of the collaborative to the time of the data collection of this study, may be a contributing factor to the lack of awareness of a quality improvement collaborative portrayed by participants. Any efforts of an awareness campaign in the participating sites in the initial stages of the collaborative may not be accurately reflected in the results of the findings owing to the turnover of patients. On the other hand, within the residential site no new patients were admitted to the unit since the collaborative process began. In spite of this, only 2 participants from an overall total of 7 interviewed knew of the collaboratives' existence.

### **5.2.2 Partnerships**

In essence, patient and carer participation could indeed be utilised to foster empowerment and fuel partnership between patients and carers and health care providers. Effective relationships are deemed pivotal in patient- centered care (Larsson *et al.* 2011). Indeed the results of this study's findings, exhibited a positive relationship between the health care professionals and the carers in the PCA. These carers attributed their understanding and awareness of PU prevention to the support mechanisms, communication and education provided by the PHN and the HCA affiliated with the health centre. In addition, the sense of empowerment that existed among participants in the PCA and also within the residential site is as a result of the established relationships, trust and facilitation that developed between health care professionals and patients and carers over the years. Partnerships such as these could be utilised more, to make meaningful strides in engaging patients and carers in participation in PU prevention strategies. This is a positive connotation for future Pressure Ulcer to Zero Collaborative efforts. These partnerships could be accentuated more so in other residential sites

and PCAs, where patients are in the care of these health service areas for extended periods and appear more comfortable in their surroundings.

Concordance exists between the findings of this study and the exiting literature where it is clearly articulated that partnership or shared decision-making is a necessary process in healthcare (Coulter & Ellins 2007). Shared decision-making underpins participation through the recognition of the beliefs and values on which negotiation is based (Sahlsten *et al.* 2008, Constand *et.al* 2014). Accordingly, this encompasses the contributions of patients and health care professionals and their relationships with one another (Weingart *et al.* 2011). Empowering patients and carers through equal partnership, participation and knowledge acquisition (Nygardh *et al.* 2011), could enable patients and carers to understand what a PU is, how they develop, their effects, and how prevention strategies using the elements of SSKIN can be incorporated into their lives.

Patient and family centred care has been acknowledged as an integral dimension in healthcare quality, where healthcare is designed and delivered to meet the holistic needs and preferences of patients (IOM 2001, National Asthma Council Australia 2007, Groene *et al.* 2014, The Picker Institute Europe 2015). Ultimately this gives rise to greater patient responsibility and usage (International Alliance of Patient Organisation 2006), leads to patient satisfaction and improved quality of life (Constand *et al.* 2014) and leads also to a more cost-effective system (National Asthma Council Australia 2007). Furthermore, the evidence that prevails in the literature heralds the benefits of patients' participation to assist in the prevention of adverse incidents and practice errors (Vaismoradi *et al.* 2014). Conclusively this engenders improved quality care (Weingart *et al.* 2014) and better safer healthcare for everyone (DoHC2008).

From theory, in its simplicity, the evidence that lends support to the use of patient centred care in PU prevention is, in practice, imperative to reducing overall prevalence and incidence rates of PUs. Take for example, from the findings in this study, participants cited that the surface supports were a contributing factor to their level of discomfort and they would have like to have been informed of the availability of alternate surface supports. By paying more attention to and

addressing the patients' holistic needs and preferences, the results could manifest an increased satisfaction in their level of comfort. Respectively, this allows them to take more control and responsibility in their repositioning and ability to move. Ultimately this contributes to an enhanced quality of life, improvement in care quality and safety thereby resulting in the avoidance of a PU developing. As evidenced within the literature, the patient's preference should assist in guiding the treatment choice (Coulter & Ellins 2007). For this to occur, patients need to be informed of their treatment choices.

### **5.2.3 Communication**

Patient and family centred care, nursing bodies, public opinion and legislation all stress the importance of patients and carers rights to participate in planning, decision making and performing activities concerning health care (DoHC 2008, Sahlsten 2008, HIQA 2012, International Alliance of Patient Organisation 2014, WHO 2015). However, it must be acknowledged that the capacity for patients and carers to participate in decisions and take responsibility in managing their health is not a choice upon which they can act alone. It seems logical in order for people to share decision making and to participate more effectively in PU prevention, they need to be armed with information, confidence and have the appropriate skills, knowledge and support to do so. For example, as identified by one participant in this study, for patients to take more responsibility in their own care, it must be a 'two way street' between health care professionals and patients. Health care professionals need to communicate the risks of PU development effectively. Discussions should include the choices of preventative interventions that may be employed, all the while remaining attentive and respectful of patients' preferences. In reciprocation, patients need to listen to, co-operate and actively engage in activities. However, one of the most pertinent findings in this study emanates from some participants beliefs that they were not involved in their pressure area care because they were not told about it. Although there is evidence within the narratives to show that pressure area care was being provided to these participants, they did not realise that it was happening. Moreover, although they were to a certain degree taking part in activities, they did not feel involved simply because it was not communicated to them.

Manojlovich *et.al* (2015) suggests that communication involves two paradigms; communication as a transactional process which is responsible for information exchange, and communication as a transformational process which is responsible for causing change. As evidenced within each theme and subthemes of the findings of this study, communication as a transactional process is lacking in some areas, thus impeding the transformational process. Subsequently this has been a major influencing factor on patients and carers lack of awareness, knowledge and participation in pressure area care. On the other hand, where communication has been delivered on PU prevention through an effective transactional process, the outcome generated in the transformational process is witnessed in patients and carers knowledge and active engagement in care. Therefore communication as a 'two-way street' between health care professionals and patients and carers, plays a fundamental role in involving and engaging patients and carers as active participants in pressure area care. From the evidence within this study, communication holds the key for the success of patient and carer involvement in PU prevention. Therefore careful consideration needs to be given to this concept for future undertakings in spreading the Pressure Ulcers to Zero (HSE 2013a) collaborative.

Communication between health care professionals and patients and carers has been identified as a central component to patient centred care (McCabe 2004). Strong communication links have proven effective in implementing the care bundle approach to quality improvement. (Resar *et al.* 2012, Whitlock 2013). Nevertheless, within this study, many patients reported that they did not feel involved in pressure area care, because they were not told about it. This is not a novel concept as supporting evidence is compounded within the literature that poor communication within healthcare is a common problem (McCabe 2006, Manojlovich *et al.* 2015). Consequently, this lack of communication may result in health care professionals making assumptions about what type of care a patient needs or wants in relation to PU prevention, simply because they do not ask patients. Supporting literature suggests that this type of communication is not patient-centred and can adversely affect the development of any positive partnerships between patients and health care professionals (Booth *et al.* 1996,

McCabe 2006), which is essential for the provision of quality patient care (Coulter & Ellins 2007).

One of the findings of this study, identified from participants' observations, was the time constraints of health care professionals due to increased workload and staff shortages. This was deemed a contributing factor for the lack of communication among patients, carers and health care professionals. This is an important consideration for PU prevention as the literature has suggested that there is a relationship between inadequate hospital nurse staffing and increased risk of adverse patient outcomes, including mortality (Buerhas *et al.* 2007). Indeed it was concluded in a systematic review conducted by Lankshear *et al.* (2005) that higher nurse staffing levels and appropriate skill mix are associated with improved patient outcomes.

The variety in patients knowledge reflected in different sites, suggests more effective communication occurs in well established nurse- patient relationships through continuity of care. Similar opinions have been identified by Sahlsten *et al.* (2009) and Larsson *et al.* (2011) with suggestions that more time should be allocated for interaction and communication in order for the patient and nurse to get to know each other. However, in reality, this may not be a possibility particularly within the acute settings. With continuous staff shortages and lack of resources an ongoing issue, more emphasis needs to be placed on the multi-disciplinary teams (MDT) to work collaboratively to provide patient centred care in PU prevention.

#### **5.2.4 Multi-disciplinary Team Involvement**

Evidenced within the literature review is the valuable role that MDTs play in pressure area care (Gould *et al.* 2000, Saliba *et al.* 2003, WOCN 2009, Jaul 2010, Moore *et al.* 2014b). Conjointly, strong multi-disciplinary links have been endorsed in the use of the SSKIN care bundle (Gibbons *et al.* 2006) (Resar *et al.* 2012, Whitlock 2013). Within this study there were varying reports from participants on how involved MDT members were. Some participants referred to MDT members as being heavily involved in pressure area care. An exemplar includes the efforts of the Occupational Therapist in the residential site which was easily



distinguishable from the patients' knowledge surrounding their personal wheelchairs and support surfaces. On the contrary, other participants across the sites had no re-collection of ever meeting certain MDT members with some expressing confusion over the different roles, for example the role of the physiotherapist versus the occupational therapist. Furthermore, although MDT members may have been involved in participants care, it was revealed that no information had been given by them regarding PU prevention.

The nurse was identified among the majority of study participants as the linchpin in delivering the most significant amount of information on PUs and prevention strategies, albeit in varying degrees within each site. The literature review identified that although the nurse has a significant role in PU prevention, the responsibility should not lie solely with the nurse (Moore & Price 2004). No one profession has all the required skills to manage this cohort of patients (Moore *et al.* 2014a). In line with existing literature and given the overall specialities linked within each element of the SSKIN care bundle (Gibbons *et al.* 2006), this finding is therefore surprising. As collaborative teams at each site were composed of MDT members, this finding has significant meaning for planned efforts to further rollout the Pressure Ulcers to Zero (HSE 2013a) collaborative.

Within the PCA, alongside the PHN, the HCA affiliated with the primary care centre was listed by carers as offering valuable information on PU prevention. Simultaneously, the carers within the PCA reported a stark contrast in knowledge and conflicting information among the 'agency' affiliated HCA's, who also provided PU prevention interventions. This implies the need for further education among this group. If 'agency' HCAs are not adequately educated and trained in PU aetiology, detection and prevention techniques, the results could be detrimental for patients. Indeed clinical guidelines advocate developing an education policy for PU prevention and treatment at an organisational level (NPUAP/EPUAP/PPPIA 2014). This means that private organisations inclusive of 'agencies' need to insure that an educational policy is in place for staff. Training needs to be provided in the prevention of PUs so that the 'agency' HCA is aware of any warning signs that pressure damage is occurring. Hampton (2005) suggests that improving the knowledge base and the competencies of HCAs in PU prevention would improve

quality of care. With the directional shift in health care provisions from a hospital-based system to the home care setting (Probst *et al.* 2014), this has significant implications for PU prevention strategies and indeed for the future success of any primary care area in the Pressure Ulcers to Zero (HSE 2013a) collaborative. Any planned endeavours to spread the collaborative needs to incorporate this into the program design and work in synergy with health care agencies to insure that those who provide care are educated in pressure area care. Indeed carers suggested utilising the SSKIN care bundle (Gibbons *et al.* 2006) as a means to do so.

In the overall perspective of pressure area care, HCA's are an underutilised resource. However, it is estimated that nursing aids or HCA's provide as much as 21% of bedside care (Needleman *et al.* 2002) and therefore play an important role in providing skin care and PU prevention. This is a significant amount of patient care time that could be maximized to enhance outcomes. Howe (2008) explored this concept by devising an educational programme designed for HCA's in PU prevention. By empowering HCA's the outcome of the education programme witnessed a decline in PU incidence from 2.17% in 2002 to 1.71% in 2003. The educational program was considered a contributor to the improved patient outcomes. Additionally, cost and time savings were noted derived from the standardization of bathing and incontinence product utilization within the program. Vuolo (2014) explicates how in one London Trust, information on PUs is provided by HCA's to all patients on admission using a written guide as a prompt. However, clinical guidelines connote that the overall responsibility for delivering PU information should lie with a trained or experienced health care professional (NICE 2014). Nonetheless, if nurses are entrusting responsibility to HCA's to provide information on PUs HCAs must be adequately educated and versed in pressure area care and PU prevention strategies.

### **5.2.5 Readiness to Participate**

Empowering and educating patients about their health and wellbeing provides them with the opportunity to have some control over what happens to them (Nygardh *et al.* 2011, Larsson *et al.* 2011, Patient Information Forum 2012). This is an important facet for those participants within this study, who expressed that they relied on others to assist in aspects of their daily care pertaining especially to skin

inspection, hygiene needs and mobility. Whilst a marked distinction is visible between the levels of dependency required among patients in each site, there is also somewhat of a similarity. Notably, at some point in their trajectory of care, most patients expressed a form of reliance and dependency on health care professionals to perform tasks. However where the difference lies, emanates from the empowerment and level of control that patients displayed when partaking in their own care despite their physical dependency levels and reliance on health care professionals. This is characterised in the findings of the study particularly within the PCA and residential site, where patients took ownership of their pressure area care. Through simple methods of seeking information, sourcing health care aids and communicating with the necessary health care professionals, this rendered them in control of their care and to a significant extent independent in their decision making. An exemplar from the findings acquired from the residential site, clearly demonstrates how one patient (with significant paralysis) was in control of their pressure area care. The extent of their involvement included seeking feedback from health care professionals of the skin inspection, with a requisition for a photograph to be taken to allow for self inspection. Following detailed discussions the patient was fully involved in the decision making process, with their preferences conveyed on the subsequent treatment plan.

Implicit in the decision making process as evidenced within the findings of this study, is the patient and carers readiness to take part and take control. Tutton (2005) postulates that patient participation is a dynamic process that changes over time. This is an important concept for patients within their trajectory of care, particularly within the acute site. The findings of this study illustrated a reliance on health care professionals that was borne at a time where patients reported they were at their most vulnerable and with minimal self control. Collectively, as a result of contributing factors associated with hospitalisation, their role as a patient and post-operative recovery interfaces, many patients communicated their inability to perform tasks for themselves, while some revealed a sense of apathy to take part. Comparable findings were reported by Larsson *et al.* (2011). Clinical judgement is therefore required by health care professionals, as to when patients are ready to receive information about pressure area care and when they can actively participate in their own care. Nevertheless, while many participants recalled being

turned frequently from side to side in the early post operative stages and alluded to their skin being inspected regularly, information as to why these interventions occurred was not provided to them. Indeed the lack of verbal communication between health care professionals and patients and carers was evident among some participants. Within the acute site, some patients expressed their frustrations at having to wait for nurses to come to their assistance to aid in repositioning. This was notably a marked deviant in their care from previously being nursed on a one to one basis on the higher dependency units. It was reported that this frustration, the gradual detachment from medical devices and their progression in recovery following surgery, were determining factors in participating in self care activities including relief of their pressure areas. Consequently it allowed for a restoration of their control in self management thus relinquishing their reliance on health care professionals.

In contrast, those patients who revealed prior knowledge of PUs whether through personal or professional experience, proposed that this was in part the impetus for which they took control of their own care as soon as possible in their recovery, for example through early mobilisation. Although a reliance on health care professionals still existed, these patients delineated a partnership through co-operation with health care staff. This suggests that patients were ready to engage and accept more responsibility in their own care early on in the post-operative period armed with the knowledge of the risks associated with PU development. Similar tendencies and active engagement in care were expressed by other participants within the study who had prior knowledge and experiences of PUs. Fear of developing a PU was in part the stimulus that motivated these participants to participate in PU preventions owing to their previous negative exposure to PUs. Comparable findings were reported by Schubart *et.al* (2008) and Jackson *et al.* (2010) both of whom identified from adults with spinal cord injury (SCI), that those who had experienced a PU in the past were motivated to avoid PUs in the future.

The findings in this study demonstrate a consensus among this motivated participant group, resolute in the belief that all patients need to be told about PUs as soon possible, owing to the lasting negative impact that PUs can impose. Although not all knowledge portrayed by these participants of PU prevention

techniques stemmed from evidence based practices, their inherent understanding of the importance of preventative interventions was prominent. For instance these included mobility, skin care and the surface to which individuals sit or lie on. In keeping with the findings of McInnes *et al.* (2014), who explored the acute care patients' roles in PU prevention, some participants within this study implied that they would have preferred to have known about pressure area care pre-operatively. Although consideration should be given to providing patients and carers with information on PUs prior to admission and/or on admission to a health care facility, further research would need to be conducted on the effects of this.

In a study exploring the educational needs of patients with SCI in PU prevention, Schubart *et al.* (2008) found timing of education to be a prominent factor in PU education. In accordance with the opinion of McInnes *et al.* (2014), when patients are preparing for elective surgery, reading information on PU prevention may not be deemed a priority. This was also suggested by some participants within this study who cited that they would like to receive information when they were more in the frame of mind to understand. Also, within the recruitment phase of this study, 2 potential candidates who were in the pre-operative stages of their hospital admission declined to take part in the research. The rationale was based on their belief that they had nothing to offer the study, as they were in the pre-operative stages of treatment and fully mobile. Therefore they considered themselves not be at risk of a PU even after surgery. For these reasons, patients may be more receptive to education on PU prevention when they are out of the immediate post-operative stages. Furthermore, the post operative period is a time when patients are at their most vulnerable thereby placing an inherent trust in health care professionals. Trust among healthcare professionals and patients may encourage problem solving, information exchange and increased involvement in decision making (Montori *et al.* 2006). In turn, this contributes to improvements in healthcare outcomes (Lee & Lin 2011). Advancing on this concept could elicit early patient involvement in pressure area care in the post operative period which could prove fundamental in PU prevention. This is an important consideration for prospective surgical sites in future Pressure Ulcers to Zero (HSE 2013a) collaborative strategies.

Between one in four and one in five acute hospital inpatients have a PU at any time, with most PUs identified in hospitalised patients as being hospital acquired (Posnett *et al.* 2009). Also, the majority of PUs occur relatively early, following admission (Padula *et al.* 2008) and post-operative patients have been identified as being prone to PUs (Schoonhoven *et al.* 2002, Bales & Padwojski 2009). Consequently, early communication is vital to elicit both patients and carers understanding of the risk of PU development and the need for PU prevention interventions in the trajectory of care. The difference portrayed among patients in their readiness to take part in their care is an important finding, as it suggests the need for written and verbal information to be provided recurrently. McInnes *et al.* (2014) concurs with the re-iteration of information, as patients' requirements for information varies throughout their hospital admission.

The aforementioned finding is also applicable to patients in other care settings. The literature review highlighted how up to 95% of adults with SCI incur at least one advanced (grade 3 or 4) PU (Jackson *et al.* 2010) and individuals with neurological impairment are at high risk of developing a PU (Vanderwee *et al.* 2007, Bales & Padwojski 2009). This is an area of concern for those participants' within the residential site who had significant neurological deficit through paralysis. As evidenced by one participant in the residential site who spoke of their experiences when leaving a rehabilitation facility and going home for the first time, it was cited that they were caught up in other aspects of lifestyle choices when discharged home. PU prevention was not to the forefront of their mind and as a consequence a grade 4 PU developed to the sacrum, which required surgery and long term bed rest. A similar finding was reported in the study by Jackson *et al.* (2010) who explored the main principles that determine how daily lifestyle considerations affect the development of a PU as perceived by individuals with a SCI. The results highlighted how avoiding PUs necessitates the need for prevention awareness for both short term and long term prevention.

#### **5.2.6 Carer Involvement**

While it has been shown that short and long term information is warranted for preventing PUs, emphasis could be placed on the role of carers to work in tandem with health care professionals in providing further re-iteration of information.

Chaboyer & Gillespie (2014) supports involving carers as an adaptation strategy. Indeed there are findings within this study to support this concept as provided by the carers within the acute site. They revealed that if they had been alerted to the risks of PU development they, as a family, would have made a concerted effort to encourage their family member to do more in the post operative period regarding PU prevention. As their family members health gradually deteriorated, grade 4 PUs developed to the sacrum and heels.

Further findings revealed by carers within the acute and residential sites, illustrated that they perceived themselves to have a limited role, if any, in the care of their family members. All the while they expressed how they would like to have been more involved in their family members care, rather than just perceived as 'visitors'. So, recruiting them as active participants in the patients care could have positive lasting results, not only for patients but for the service as a whole. This is an important consideration for future collaborative efforts. If more responsibility is given to carers by educating them in PU prevention strategies utilising the SSKIN care bundle (Gibbons *et al.* 2006), this could elicit further participation by patients through co-operation with their carer's, thereby promoting earlier and timelier interventions. In addition, involving carers in simple tasks, could serve as a potential to alleviate health care staff to attend to other duties. This was recognised by some participants, who acknowledged that health care staff were often too busy to provide simple PU interventions. They concluded that if they as carers were allowed more access and given more control, they could assist in performing these PU prevention interventions. However, to the writer's knowledge no evidence exists on the effects of incorporating carers in PU prevention strategies using the SSKIN care bundle (Gibbons *et al.* 2006) while family members are inpatients. Further research on this topic is warranted.

Within this study, carer participants' views coalesce how when patients are at home, the carers behold the title of primary caregiver. Yet in the acute and residential settings, they were demoted to secondary caregiver, with tasks only extending to helping family members to eat. While this is an important aspect of care, more onuses could be placed on carers to provide further PU prevention interventions. Performing simple evidence based tasks such as reminding and

assisting their family member to mobilise (when indicated), offload heels or perform skin care, could serve as an invaluable resource.

Inevitable changes are forthcoming in health care provisions from a hospital-based system to the home care setting (Probst *et al.* 2014). Therefore, it will become more of a commonality that carers become primary caregivers in the home setting and will be providing assistance with the aforementioned tasks and more. This can be witnessed in this study from the carers within the PCA who were central to the delivery of their family members care at home. Carers are the keepers of valuable information (Institute for Patient & Family Centred Care 2010), such as patient preferences, bestowed to them as a result of their relationships with their family members. If situations allow, it seems logical to impart carers with a more active role in the care of their family member in the acute and residential sites. As such, eliciting carers in PU prevention utilising the SSKIN care bundle (Gibbons *et al.* 2006) holds promise for future successful collaborative endeavours.

### **5.2.7 The Need for Change**

Traditional models of health care placed emphasis on restricting patients and carers (Institute for Patient & Family Centred Care 2010). In contrast, the patient and family-centred approach accentuates the strengths that patients and carers can bring to health care delivery (IOM 2001, National Asthma Council Australia 2007, DoHC 2008, HIQA 2012, Groene *et. al* 2014, International Alliance of Patient Organisation 2014). From the findings in this study, there appears to be a gap from theory to practice in engaging patients and carers in PU prevention strategies. There is a need for change in practices when adverse events occur, such as the presence of a hospital acquired PU, which is seen as a quality care indicator (DoHC2008, Moore 2010, NPUAP/EPUAP/PPPIA 2014, HIQA 2012). For that reason, there is an inherent need for a change in practice to involve patients and carers in PU prevention strategies. Bearing that in mind, as a core element of the Model for Improvement (IHI 2014), the Plan-Do-Study-Act (PDSA) cycle is utilised as a powerful tool for selecting, testing and implementing changes for quality improvement. Although it may require a long term commitment, the PDSA cycle can be used as a means to continually explore and evaluate new ways to involve and collaborate with patients and carers in PU prevention interventions. In



addition the PDSA cycle could also be utilised to encourage measuring patient engagement in self care.

### **5.3 'Prevention is Better Than Cure'**

PU's are largely problematic (Defloor *et al.* 2005, Riordan & Voegeli 2009, Moore *et al.* 2013a), yet highly preventable (Gallagher *et al.* 2008, Moore *et al.* 2013b, NICE 2014). As a result the SSKIN care bundle (Gibbons *et al.* 2006) has been developed as a comprehensive plan to define best practice to assist in eliminating PU's through prevention (IHI 2011, Healthcare Improvement Scotland 2011, Resar *et al.* 2012, Whitlock 2013). Therefore as one of the key objectives of this study it was important to acquire an understanding of participants' knowledge and perceptions pertaining to the role of the SSKIN care bundle (Gibbons *et al.* 2006) in preventing PU's. The findings demonstrated how the majority of participants believed that prevention plays a vital role in pressure area care. Many participants conveyed that prevention was the primary facet of pressure area care. Indeed, 'prevention is better than cure' was well versed among study participants. This is an important consideration as it illustrates a pre-conceived awareness among individuals that prevention holds the key to the avoidance of PU's, which provides a basis on which to cultivate their knowledge base.

#### **5.3.1 SSKIN- what participants think**

Findings within this study show that for the most part, not many participants knew about the SSKIN care bundle (Gibbons *et al.* 2006). This was, in part, owing to the different quality improvement techniques adopted in collaborative sites. For example the PCA used the acronym 'PROMPT' and in the residential site, although no acronym was used, each core component of the SSKIN was utilised in individualised care plans. Interestingly, many participants had no prior knowledge of the SSKIN care bundle (Gibbons *et al.* 2006). Yet, despite the confusion that existed around SSKIN versus skin, the majority of participants were in agreement that the concept of the SSKIN care bundle (Gibbons *et al.* 2006) was a good idea. For the most part, the majority wished they had heard about it sooner, prior to the study. This impression emerged following the detailed discussions in the interviews on each element that comprises the acronym SSKIN. These

discussions elicited opinions from participants on both the causative and preventative features associated with PUs.

Another thought process that emerged from participants, delineated how the SSKIN care bundle (Gibbons *et al.* 2006) should be targeted towards those who were more at risk and lived alone in the community. This resembles the findings of Gillespie *et al.* (2014) where study participants highlighted how a three component care bundle should be aimed at high risk patients, as they felt that they would benefit from it the most.

Interestingly, the findings identified 2 participants who, despite their restricted mobility, believed themselves not to be at risk of a PU because they had not previously acquired one. They highlighted how the SSKIN care bundle (Gibbons *et al.* 2006) could serve as a guide for them in the future. Further examples from the findings include another 2 patients who believed that PUs could not be prevented. Following discussions of each element of SSKIN their opinions changed and reverted to how prevention would be important in pressure area care. So, these findings exhibit how communicating and sharing information can change perceptions and help patients and carers understand the importance and relevance of PU prevention. In turn this has the potential to make significant contributions to creating awareness on pressure area care, and PU prevention adopting the SSKIN care bundle (Gibbons *et al.* 2006). This is a promising finding and holds meaning for future collaborative efforts to promote PU prevention strategies.

The primary cause of PUs is prolonged unrelieved pressure from lying or sitting on a particular part of the body, usually over a bony prominence (Theaker 2003, Defloor *et al.* 2005, Moore *et al.* 2011, NICE 2014, NPUAP/EPUAP/PPPIA 2014). When participants were asked on their initial thoughts of how a PU develops, many identified pressure as the causative factor and/or immobility was ranked highly as another accounted causative factor. Others merged the two. This finding is in support of well referenced literature (Moore & Cowman 2011, Moore *et al.* 2011). When participants were asked on their initial thoughts of how PUs could be prevented, a general consensus existed on the role that mobility plays in the

avoidance of the development of a PU. This is in keeping with previous patient experiences study findings (Spilsbury *et al.* 2007, McInnes *et al.* 2014).

The study's findings have shown that during the discourse of the interviews, and upon discussion of each element of the SSKIN care bundle (Gibbons *et al.* 2006), opinions evolved. The result of which illuminated skin inspection, surface and keep moving to be deemed the most important elements from SSKIN in PU prevention. The rationale for which derived from the following concepts. Early inspection of the skin in its primitive role was considered imperative for the early detection and timely treatment of PUs and this view is supported in the literature (Guy *et al.* 2013, Moore *et al.* 2013c, NICE 2014, NPUAP/EPUAP/PPPIA 2014).

The right surface was highly favourable among participants as a key feature of PU prevention, mostly due to the comfort, support, control and flexibility of interchangeable positions that pressure redistribution devices and electronic beds could offer. Those who were restricted in mobility valued the right surface to sit or lie on, with carers in the community praising their availability. Clinical guidelines advocate the use of pressure redistribution devices in the at risk patient (NPUAP/EPUAP/PPPIA 2014). Contrasting experiences of participants within the sites are notable, owing to the lack of available pressure relieving equipment offered and/or the old style lever hospital beds to which some participants negatively reviewed. Keep moving was considered the determining prerequisite to PU prevention. Many participants recognised that sitting or lying for long periods in bed could result in the development of a PU, thus inducing the need to mobilise. For some patients it was acknowledged that they need full assistance with this and would therefore call upon the health care professionals frequently.

While acknowledgement was attributed to incontinence and nutrition as important factors in PU prevention, it appears to a lesser degree. This may have been as a result of an insufficient knowledge base on their role in PU development or they may not have been specific to their individual personal needs. In addition, the majority of participants did not discuss their continence status during the discourse of the interviews compared to that of the preliminary meeting. As Holroyd (2015) postulates, incontinence can have a distressing effect on the physical,

psychological and social quality of life of those affected and can lead to feelings of isolation, anxiety, depression and embarrassment. As a result, these participants may not have been comfortable revealing such personal details in a recorded interview. When participants spoke of Incontinence issues, good hygiene and skin care were alluded to as important aspects in PU prevention. Indeed, skin care is advocated in PU prevention strategies (NPUAP/EPUAP/PPPIA 2014, NICE 2014). Even though many participants could not fully articulate why it contributes to PU prevention, they concluded that it played an important role. Confusion also existed on the different skin care products available for example emollients and moisturisers. This was mostly evident among the elderly population interviewed. This is an important concept as although incontinence can affect all age groups, a higher incident exists among the elderly population (Cooper *et al.* 2008). Coupled with the evidence that PU development increases proportionally with age (Edsberg *et al.* 2014), and the expected rise in the elderly population in Ireland, this suggests that further education and information on this component of the SSKIN care bundle (Gibbons *et al.* 2006) is warranted. This is an important consideration for future collaborative efforts as most care settings provide care to the older population group.

The role of nutrition in the prevention of PUs also appeared to have a lesser prominence within the SSKIN care bundle (Gibbons *et al.* 2006) among participants. Nonetheless nutrition was described by many to be an important contributing factor in PU prevention. Carers were indeed the most articulate when discussing the nutritional needs of their family members as for many, they felt this was the extent of care they could provide to them. The findings of this study demonstrated many participants were unaware as to what extent the role of nutrition played in PU prevention. Comparable findings were reported by Roberts *et al.* (2014) in their study exploring hospitalised patients perceptions on the role of nutrition for PU prevention.

Notably those who had previous experiences of PUs predominantly spoke mostly of the importance of nutrition in healing a PU. Participants made some attempts at deductive reasoning as to how nutrition is important for PU prevention. The general consensus interpreted that if you don't eat, you won't have the energy to

move, thus prolonged pressure is exerted over bony areas. Also, within the findings participants reported there was a correlation with weight and PU development. This reflects evidence within the literature how patients with low body mass index (BMI) are at higher risk of PU development (VanGilder *et al.* 2009, Kottner *et al.* 2011). Indeed the literature review highlighted how poor nutrition leads to muscle wasting and tissue loss which can increase the prominence of bony areas of the body (Benbow 2008, Moore *et al.* 2011). Be that as it may, some participants believed that being overweight could also lead to PU development. However, there is conflicting evidence within the literature to support this opinion, with the distinct relationship between increased BMI and PU development uncertain (Kottner *et al.* 2011).

### **5.3.2 Comfort and the Role of Repositioning**

Participants made a distinct correlation between comfort and PU prevention. Interestingly, one participant expressed overwhelming discomfort as a result of perspiration and an immense heat that they experienced in their heels. It was further elaborated how it was only when their heels were offloaded and skin care attended to, that they experienced relief from these symptoms. Yet, it was reported that it was never explained to as to why this happened. Recent research has begun to explore the concept of microclimate in relation to PUs (International Review 2010). Evidence to date suggests that extremes of skin temperature and/or humidity/skin moisture appear to increase the sensitivity of skin to the damaging effects of pressure, shear stresses and friction. This holds meaning for future collaborative efforts on the importance of patient assessment in PU prevention.

The role of repositioning was discussed in connection with surface and keep moving, with discomfort identified by many as the rationale for repositioning. Discomfort as a reason for repositioning has been noted by others in the literature (Krapfl & Gray 2008, McInnes *et al.* 2014). Indeed, as pressure is the cause of PU development, repositioning is considered one of the best ways to prevent the occurrence of a PU (Moore *et al.* 2011, ) as it helps to shift and redistribute pressure off vulnerable areas (Defloor *et al.* 2005, Vanderwee *et al.* 2007b, Krapfl & Gray 2008). The latter is echoed throughout participants narratives, albeit

repositioning lasted only for short periods for some participants. This was due to an inability to get comfortable, thus leading to further problems in sleep disturbance and frustration. Similar findings have been reported by Gorecki *et al.* (2009), who explored the impact of PUs on quality of life in the older patients.

Repositioning varies from small changes in positioning undertaken by the patient with encouragement from staff to full lateral repositioning by health care providers on behalf of the patient (McInnes *et al.* 2013). While there is no one position suitable for all, clinical guidelines state that repositioning should be undertaken using the 30 degree tilt (NPUAP/EPUAP/PPPIA 2014). Victor (2013) recently explored patient and staff nurse's experiences of the 30 degree tilt reposition technique for the prevention of PUs. Patients reported that 30 degree tilt repositioning relieved pain and promoted comfort. While there have been significant strides in the types of equipment available, it must be acknowledged that there are still old style hospital lever beds in existence as evidenced within this study. The lack of available resources is an important consideration for future roll out of the collaborative as not all repositioning techniques may be straight forward. With this in mind the 30 degree tilt could be a useful technique to adopt into practice with pressure redistribution devices to assist in filling the void. However clinical judgement and a thorough pain assessment of the patient should also be performed as not all patients may be able to be repositioned. Involving patients in repositioning through shared decision making and patient preference should also be incorporated, as patient participation has been shown in the literature to enable patients to maximise their potential for comfort (Sahlsten *et al.* 2008).

### **5.3.3 SSKIN- all together now**

The findings of this study identified how participants revealed that at times when health care professionals made reference to pressure area care, mobility was the common attribute referred to. In collaboration with participants conceived opinions that some parts of SSKIN are more favourable than others, a potential exists for valued elements of the SSKIN care bundle (Gibbons *et al.* 2006) to dissipate. A concerted effort must be made by health care professionals to inform patients on the full elements of SSKIN in order to elicit their active participation in care. As

hypothesised by Fulbrook and Mooney (2003), the whole is greater than the sum of the parts. As such, a care bundle is formulated with the purpose of cementing all components into an individual unit of care that must be implemented for every patient on every occasion. Each individual component exerts a synergistic effect on the others thus leading to optimal performance and resulting in a greater effect on the positive outcome for patients (Downie *et al.* 2013). Consideration must be given to individualised patient needs where one component of the SSKIN care bundle (Gibbons *et al.* 2006) may bear increased emphasis over another for patients, for example incontinence may be an important aspect of care in PU prevention for one patient but it may not affect another. Nevertheless, for individuals to gain a full cognisance of the importance of PU prevention, all elements of the SSKIN care bundle (Gibbons *et al.* 2006) should be emphasised equally when education is taking place. This holds meaning for planned endeavours to spread the collaborative where emphasis needs to be placed on the SSKIN care bundle (Gibbons *et al.* 2006) as a whole package.

In synergy, education and effective communication from health care practitioners can provide patients and carers with the necessary knowledge and benefits that each element of the SSKIN care bundle (Gibbons *et al.* 2006) has to offer in PU prevention. The findings of the study revealed that while some consistencies did exist, there remained a disparity among all participants relating to topics such as physiological processes of PU development, risks, skin inspection, how often should a skin inspection be performed, what to look for, repositioning times, resources available, skin care, incontinence and nutrition. This bears meaning for future collaborative efforts as it suggests that further education and input is warranted from health care professionals. Offering patients and carers guidance on evidence based techniques and available resources associated with the SSKIN care bundle (Gibbons *et al.* 2006), can alleviate non recommended strategies such as those alluded to by participants in this study. For example, skin rubbing on detection of a red area on the skin surface and use of inflatable ring cushions as pressure relieving devices. Similar findings were noted by McInnes *et al.* (2014). Indeed, when healthcare practice amalgamates research evidence with clinical expertise and patient preferences, practice as a result improves. This then leads to

better outcomes for patients, their families and the health care system (Crunden *et al.* 2005, Leufer & Cleary-Holdforth 2009, Eizenberg 2010).

## **5.4 Health Promotion**

### **5.4.1 SSKIN – where does the confusion lie?**

The confusion that existed in the discourse of some of the interviews and also in the recruitment phase surrounding the acronym SSKIN and actual skin connotes that more thorough detailed explanations of the acronym are warranted. The re-enforcement necessary by the writer to explain each element of the SSKIN acronym was another compelling factor to support this finding. Additionally the 'Surface' component of the acronym caused further confusion, whereby some participants thought the surface referred to the surface of the skin. Notably, the elderly population experienced the most confusion. Consideration must also be taken to acknowledge those participants who expressed general literacy problems within this study and therefore did not understand which letter corresponded with each component.

The literature review unearthed a scarcity of evidence exploring the patient and family experiences of the SSKIN care bundle (Gibbons *et al.* 2006), therefore to the writers' knowledge, no evidence of this finding has been previously reported. Notably, Gillespie *et al.* (2014) devised a PU prevention care bundle comprising of 3 core preventative components; 1. Keep moving 2. Care for your skin and 3. Ensure a good diet. Following interviews of 21 participants, 7 of whom were consumers, all were able to re-iterate the 3 core messages of the care bundle. These results question whether adopting a more formal word process instead of an acronym, with fewer interventions, would elicit recall of preventative measures more readily for patients. On the other hand, within this study following in-depth discussions on each component of SSKIN, the majority of participants believed the concept of SSKIN to be a good idea. Nevertheless, much re-iteration was warranted. These findings are important for any future rollout of the Pressure Ulcers to Zero (HSE 2013a) collaborative as it calls into questions the strength of using an acronym for alerting patients and carers on PU prevention strategies.



It has been suggested that patients can struggle to make sense of health related materials with unfamiliar concepts (HSE 2015b). Involving patients and carers in the early phases of the collaborative process may highlight issues such as those aforementioned. If it is the fundamental aim to engage patients and families/carers in healthcare, it seems logical that any new initiatives should be promoted in a manner that is service user friendly and following detailed analysis of the literacy levels of health information being provided. Otherwise patients and families/carers may be at risk of misunderstanding health communications. Therefore health literacy is fundamental to patient and carer engagement. This corresponds with recommendations in a report by the National Adult Literacy Agency- 'Policy Brief on Health Literacy in Ireland' (NALA 2009). As part of its recommendations, health literacy should be considered during all national initiatives undertaken by the Department of Health. Further recommendations include that all published materials be written in plain English, incorporate images and tested with focus groups (NALA 2009).

#### **5.4.2 Health Literacy**

There is a considerable gap between what patients understand compared to what health care professionals expect them to understand (Marshall *et al.* 2012). This concept resonates within the narratives of this study where some participants expressed their frustrations of the disparity in terminology used among different health care professionals and their use of medical jargon when communicating with participants. The HSE (2015b) recognises that people who do not experience literacy difficulties in other areas of life may easily experience difficulty in healthcare settings because they are not used to the setting or indeed the vocabulary. Nonetheless, owing to the use of complex terminology by health care professionals as reported by participants in this study, it can be surmised that ignorance exists among health care professionals to the level of health literacy that extends among patients and carers. In correspondence with this, a previous Irish survey identified that over two thirds of General Practitioners do not recognise the magnitude to which literacy problems protract among Irish patients (HSE & NALA 2009). Moreover, evidence suggests that doctors over-estimate patients' literary levels and rarely consider limited literacy skills in their assessment of whether patients comprehend what they must do, in order to manage their illness (Bass *et*

*al.* 2002). A consensus exists in the literature whereby increased awareness is necessary among health care professionals in the levels of health literacy, with recommendations that training be received on how to address these issues in order to maximise patient care (Schwartzberg *et al.* 2007, NALA 2009, Marshall *et al.* 2012).

Within this study the level of health literacy among the participants is easily identifiable through the variety of denominations attributed to PUs as well as their comprehension of PUs and prevention techniques. However, this could also be as a result from the variety in terminology used and lack of clarity by health care professionals when educating individuals about PUs. Given the diversity of participants included within this study, one can assume that health literacy is an issue that can challenge anyone to varying degrees. Knowing the extent to which people are able to read and comprehend health instructions is considered an important part of tailoring health services (Ministry of Health 2010). Indeed, many people find health information quite difficult to understand (Health Literacy Survey:EU 2012, Sahm *et al.*, 2012NALA 2015). As part of a recent European research study involving 8 participating countries, results indicated that 40% of Irish people found it difficult to understand health information (Health Literacy Survey: Europe 2012, NALA 2015).

The most cited definition among the literature on health literacy originates from the Institute of Medicine (2004);

*“the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (IOM 2004:2).*

International research emphasises a direct association between a person’s level of literacy and their health status (IOM 2004, Ministry of Health 2010, Health Literacy Survey: Europe 2012). Further evidence indicates that inadequate health literacy impacts negatively on health outcomes (Health Literacy Survey: Europe 2012, Marshall *et al.* 2012), delays diagnosis, results in poor disease management skills, and is linked with higher health-care costs (Schwartzberg *et al.* 2007). In addition,

patients with limited health literacy may have worse self management skills, lower use of preventative services, poorer medication adherence, higher hospitalisation rates and higher rates of mortality (IOM 2004, Sahm *et al.* 2012). At its essence, health literacy is fundamental to enhance the involvement of patients in their care therefore, all efforts to strengthen patient engagement should aim to improve health literacy (Coulter & Ellins 2007). Careful consideration should therefore be given to this concept for future collaborative efforts.

The findings of this study identified the elderly population to be in most need of further detailed explanations of the elements of SSKIN. Similarities exist among health literacy studies, whereby the elderly population have been identified as a vulnerable group in poor health literacy (Cronin *et al.* 2011, Health Literacy Survey: Europe 2012). In addition, the literature review depicted that PU development increases proportionally with age (Edsberg *et al.* 2014). Also with the changing population demographic and the expected rise in the elderly population in Ireland, the incidence and prevalence of PU is set to rise (Moore & Cowman 2011). Collectively, this is a worrying concept. Consequently, if the Pressure Ulcers to Zero (HSE 2013a) collaborative is to succeed on a national scale in its efforts in reducing overall incidence and prevalence rates of PUs, there must be a concerted effort by all stakeholders to address health literacy needs among this vulnerable population group.

The recently published 'Healthy Ireland- A Framework for Improved Health and Wellbeing 2013-2025' (DOH 2013) demonstrates a commitment to '*address and prioritise health literacy in developing future policy, educational and information interventions*' (DOH 2013:25). Prominent influences for dissipating health literacy are verbal and written formats which have been shown to improve knowledge, reduce hospital admissions and increase satisfaction levels regarding patient and carer education (Hartigan *et al.* 2011). However, patient education and information aids should be aimed at an appropriate level for the target population (Cronin *et al.* 2011). Additionally written materials for health information have been deemed most effective when synthesised with, rather than replace, interactions between patients or carers and health care professionals (Coulter & Ellins 2007). This sentiment reflects the wishes of participants in this study. Although it was reported

by participants in the acute site that the posters and information leaflets were useful, many communicated that they would have preferred to have been informed about PU prevention.

Although written health materials are well-founded information sources for many patients, they may be difficult or even inappropriate for those with low health literacy (Schwartzberg *et al.* 2007). Studies indicate that patients with low health literacy are more likely to rely solely on verbal instruction from their health care provider (Schwartzberg *et al.* 2007). This sentiment is mirrored in the writer's reflective incident exhibited in the findings. When one of the study participants revealed that they were illiterate, the result necessitated the writer to tailor further meetings with participants to incorporate health literacy levels. As such, health care professionals need to deliver health information that concurs with patients and carers ability to understand, thus enabling them to make informed choices about healthcare. In effect, health literacy on pressure area care should be delivered in a variety of formats that compliment an individual's ability to comprehend the information being provided. Providing patients and carers with verbal, written, pictorial or multimedia information, enables and empowers patients to self- manage and make informed decisions regarding health choices (Hartigan *et al.* 2011).

#### **5.4.3 Spreading the Word**

Education is fundamental to patient participation (Lusk & Fater 2013, Vaismoradi *et al.* 2014). Furthermore education is considered an important aspect in PU prevention programmes (Gethin & Mc Intosh 2014, Gillespie *et al.* 2014) and is an essential component in the SSKIN care bundle (Gibbons *et al.* 2006) (Resar *et al.* 2012, Whitlock 2013). Indeed, clinical guidelines emphasise the importance of offering timely, information to individuals deemed at risk of developing a PU (NICE 2014, NPUAP/EPUAP/PPPIA 2014). However, for patients and carers to understand ways to prevent PUs, they must first need to know what a PU is and how they develop. The findings of this study demonstrate that those who had previous personal or professional experiences of PUs displayed a good knowledge base of PUs and preventative interventions. The carers within the PCA also

exhibited a good knowledge base owing to the education, support and guidance provided by the PHN and the HCA affiliated with the PCA.

The findings showed that the majority of participants paid a vested interest in learning more about PU aetiology as well as prevention techniques. Indeed, as already stated most relayed that they would have liked to have heard about the SSKIN care bundle (Gibbons *et al.* 2006) as a means in preventing PUs sooner i.e. prior to the study taking place. This was indicative in the interviews that evolved into education sessions between the writer and participants. Interestingly, carers within the acute site reported that when they were informed and educated by health professionals of the NPUAP/EPUAP/PPPIA (2014) grading system they found this most beneficial in understanding the extent of their family members PU. There is evidence to suggest that when patients and carers are provided with a solid knowledge base about disease process and treatment, the outcome is more favourable (Boswell 2007, Wright- Nunes 2013). Indeed clinical guidelines recommend that information given to individuals on PUs should include the causes of PUs and early signs of development (NICE 2014). While there is a potential to incorporate information of the PU grading system into educational tools, this information may be specific to personalised individual needs or it may be more beneficial as part of an educational tool related to PU treatment. Further research of the benefits of incorporating such information would need to be explored.

Health information, decision aids and educational tools have been shown to be effective in increasing the participation of patients and carers in decision making and health care (Ward & Hawthorne 1994, Asbury & Walshe 2005, Coulter & Ellins 2007, Cronin *et al.* 2011, Hartigan *et al.* 2011). This study's findings indicate that the media outlets utilised in the acute site i.e. the posters on display, the information leaflets and the staff badges displaying 'Think SSKIN', were significant contributory factors for those study participants' who were aware of the acronym SSKIN. While in the PCA, the use of the magnetised fridge PROMPT cards, were proving to be a useful reminder to other family members and 'agency affiliated HCA's'.

While this study did not set out to explore the effects of each individual educational tool utilised in the care settings, the findings revealed rich data from participants of their preferences in obtaining information on pressure area care and the SSKIN care bundle (Gibbons *et al.* 2006). The myriad of prospective ideas that emerged from participants within this study reflects the range of sources and formats from which individuals prefer to obtain and access information most suited to their health literacy level. The well known idiom 'prevention is better than cure' was cited by many participants throughout the discourse of the interviews in this study, suggesting a recognition by participants of the lasting effects that PUs can impose on an individual. Indeed this was also quoted by participants in the study undertaken by McInnes *et al.* (2014), examining the role of patients in PU prevention. Within the findings of this study one participant brought forth the notion that, as this is a well versed idiom among individuals, it's combination in some format with the SSKIN care bundle (Gibbons *et al.* 2006) could aid in creating awareness of pressure area care as well as provide individuals with a sense of how damaging PUs could be.

The prospective ideas that emerged is also suggestive of patients and carers enthusiasm and willingness to contribute to service planning as well as engage and be more involved in their own care or the care they provide as caregivers. While some participants reported on the benefits of the poster, others reflected on how they would have like to have had a small card at the bedside, to serve as an aid memoire to remind them to turn. In a study by Chaboyer & Gillespie (2014) where the nurses' views on a PU prevention care bundle were explored, nurses advocated the use of resources such as a checklist, poster, brochure and video to act as cues and visual reminders for patients. Coupling this with the carers positive attitudes towards the reminder cards of PROMPT, this is a positive finding to promote awareness and involvement in pressure area care. This finding also underscores the evidence that merits the availability of tangible health information relating to health conditions that promote awareness, thus empowering patients to maximise their health and participate in self- care (Mancuso 2008, Hartigan *et al.* 2011). It can also be linked to Anger *et al.* (2009) hypothesis that empowering patients through health literacy is positively linked to happiness.

The findings of this study demonstrated that some participants would find one to one conversations with health care professionals most beneficial to receive education about PU prevention. Others cited how they would like to speak with other patients or families to share their experiences of PUs and potentially learn from them. While there appears a scarcity of evidence within the literature exploring the benefits of patients teaching patients, there is a suggestion that social interaction, empathy and peer support can be influential in assisting patients to manage their own conditions (Vuolo 2014).

From this study's findings, working in partnership with patients and carers to devise educational tools could result in the formation of simple albeit effective comprehensive aids suited to varying health literacy levels among patients and carers. What health care professionals think may be valuable information, may not reign true for patients and carers. In line with this, while the acronym SSKIN may be favourable among health care professionals, it may not be suitably targeted towards health care service users. This can be evidenced from the confusion portrayed by participants surrounding the acronym SSKIN and skin. This concept is supported by Jeske *et al.* (2006) who detailed how as part of a quality improvement program, nurses partnered with patients and families in a medical unit, to design and implement an educational poster in falls prevention utilising the Plan-Do-Study-Act process. Ongoing feedback was sought from patients and families to modify the poster until it was appealing and deemed effective. Interestingly, when the process began, the poster included fall prevention information that staff thought was crucial for patients, however over the course of numerous PDSA cycles, patients and family members reported consistently that the poster had too much information and too small a font size. A patient's suggestion of a stop sign as a familiar visual cue resulted in the successful development of the final poster. The overall efforts of the poster resulted in a marked decrease in falls on the unit.

This finding holds valuable meaning for future Pressure Ulcers to Zero (HSE 2013a) collaborative efforts. It seems logical that piloting test and gaining feedback of materials from service users on suitability and ease of comprehension could be a simple step towards improving health education materials on PU prevention.

This could be of particular importance for the older population. Gillespie *et al.* (2014) emphasises how feedback from patients on the content and components such as readability and formatting within written materials, can be a contributing factor in engaging a broad group of patients.

Use of patient information leaflets is an invaluable method to provide patients with information and educate them about their healthcare in an accessible manner (Asbury & Walshe 2005, Cronin *et al.* 2011, Hartigan *et al.* 2011). While some participants acknowledged that the leaflets were informative, they reported that they did not answer some of the questions that they had. This concurs with Coulter & Ellins (2007) who posit that written materials for health information have been deemed most effective when synthesised with verbal communication.

The added influences of leading staff members 'modelling' within the visual informational aids within the acute site of this study was indeed a contributing factor in grasping the attention of 4 from 7 of this sites patient participants. Following an extensive search of the literature, to the writers' knowledge, there is no evidence to corroborate the use of familiar staff in advertising health promotion campaigns. However in a superior league, utilising familiar faces such as celebrities within advertising campaigns has been endorsed as a valuable strategy for decades. Multiple companies capitalise on public recognition of celebrities in advertising consumer products and services (Choi *et al.* 2005). The feasibility of modelling a celebrity or a key staff from each ward at each site may not be a realistic approach. Be that as it may, the literature highlights that endorsers of a product represented in advertising methods are the prime visual components of the advert. Additionally they are most likely to be remembered as the source of the advert message (Bhutada *et al.* 2012). Irrefutable evidence of this exists from the most recent and highly advertised QUIT campaign (HSE 2013d) which saw Gerry Collins, who died from tobacco-related lung cancer, become an Irish household name through hard-hitting and powerful anti-smoking adverts. The HSE estimated, based on uptake of services, that over 200,000 quit attempts were made in Ireland since these adverts commenced with an overall reduction of 70,000 in the number of smokers in 2014 (HSE 2013d).



This campaign was referred to and recognised in this study by participants as being highly effective. Some participants suggested using a media campaign similar to the aforementioned would be beneficial in creating awareness on PUs and prevention techniques. Others cited how using an in-house video campaign to promote the existence of the Pressure Ulcers to Zero (HSE 2013a) collaborative and provide relevant information pertaining to PU prevention would be beneficial. Participants offered some valuable ideas on ways to promote and educate individuals in pressure area care and PU prevention using the SSKIN care bundle (Gibbons *et al.* 2006). While these ideas should be considered for future planning in the spread of the collaborative, further research needs to be conducted to evaluate these methods.

## **5.5 Conclusion**

This chapter has discussed the findings of the study which explored the patient and carers experience of implementing the SSKIN care bundle (Gibbons *et al.* 2006) within a regional quality improvement collaborative. As part of the Pressure Ulcers to Zero (HSE 2013a) collaborative initiative, it was envisaged that a patient and carer centred approach be adopted by collaborative teams to improve healthcare methods in relation to PU prevention using the SSKIN care bundle (Gibbons *et al.* 2006). However the rhetoric of patient awareness and engagement in collaborative planning and activities does not appear to be a reality in practice. Only a minimal number of participants knew of the Pressure Ulcers to Zero (HSE 2013a) collaborative. In addition, levels of patient and carer knowledge and involvement in pressure area care and PU prevention was fragmented across settings. Particular attention needs to be given to patients and carers readiness to engage in their trajectory of care. Be that as it may, changing practices need to be implemented in health service organisations, to encourage and engage patients and carers to assume a more active role in shared decision making and self care in PU prevention strategies. When patients and carers are involved in shared decision making in managing their health care, this yields better outcomes.

The SSKIN care bundle (Gibbons *et al.* 2006) was not recognised by many participants part owing to the varying techniques adopted in each care site in pressure area care. Much confusion was portrayed by participants surrounding the

acronym SSKIN and actual skin. Following cognisance of its meaning relating to PU prevention it was deemed to be a good idea. However this was following detailed re-iteration of each element of SSKIN by the writer. Further confusion was witnessed on the 'Surface' element where participants believed this to refer to the surface of the skin. This implies that attention needs to be drawn to barriers such as knowledge and health literacy among patients and carers.

A concerted effort by all collaborative stakeholders to address health literacy needs among patients and carers has important meaning for any future success of collaborative efforts. Providing education through verbal and written methods at a level that patients and carers can understand is fundamental to the avoidance of PUs. The support from the MDT teams is important for encouraging and educating patients and carers in self-care in PU prevention. Ultimately from the findings of this study, communication as a 'two way street' between patients and carers and health care professionals holds the key for any future success of attaining a goal of getting Pressure Ulcers to Zero.

## **Chapter 6**

# **Conclusions and Recommendations**

## **6.1 Introduction**

The purpose of this research was to explore the patient and family/carer experiences and involvement of implementing the SSKIN care bundle (Gibbons *et al.* 2006) within a regional quality improvement collaborative. This chapter will draw on conclusions and make recommendations arising from the findings of this research study. This chapter will be divided into five sections. The first section will discuss the strengths and limitations of this study in the context of the research design. This will be followed by a discourse on the possible implications for practice, management and education together with recommendations for future research and planning in the spread of the collaborative. The fourth section will outline the dissemination plan for the study findings and outputs. The fifth section includes a reflection of the writer's personal journey throughout the research process. This is followed by a conclusion, bringing together the salient points arising from this work.

## **6.2 Strengths and Limitations**

This study has a number of strengths. Foremost, this study sought and received ethical approval from three research ethics committees; one in the acute site, one in the affiliated university and the other covering primary care. This confirms that the study met the ethical standards for conducting this piece of research in the chosen settings and all ethical principles were duly upheld (ABA 2007, HSE 2013c, NMBI 2014). In addition, throughout the research process the writer maintained a reflective journal. As a novice researcher, it was imperative that the writer identify and reflect about on biases, preferences and progress in the field of inquiry. This enabled self- examination and self- monitoring of the effect of the writer on the research process. Reporting reflections also allows the reader to assess any concerns about researcher objectivity and interpretations of data.

The justification for this research study stemmed from the results of a regional quality improvement collaborative within the HSE entitled 'Pressure Ulcers to Zero' (HSE 2013a), which utilised the SSKIN care bundle (Gibbons *et al.* 2006). As the involvement of patient and family/carer is a central component of health care delivery, this study set out to explore the patient and family/carer actual experiences and involvement within the collaborative including use of the SSKIN

care bundle (Gibbons *et al.* 2006). A gap exists within the literature and as such in our understanding of their experiences of being involved in quality improvement initiatives. The writer is unaware of any other research that has explored this concept. Therefore the unique findings of this study are viewed as a starting point in contributing to knowledge on this topic.

Another inherent strength of this study was the chosen research approach. The study used a qualitative descriptive approach which the writer deemed suitable to present the voice of the particular population under study. It allowed the writer to remain closer to the words and meanings offered by the rich descriptions from participants, thus providing a comprehensive summary of the phenomenon in everyday terms. Additionally, gathering the data using the semi-structured interviews provided flexibility and a chance to explore issues that arose spontaneously and ask additional questions. This presented the writer with the opportunity to explore new paths that emerged as the interviews and focus groups progressed. For that reason, rich valuable information was elicited from participants thus adding to the strength of the overall findings of the study.

A further strength of this study is that the patients interviewed reflect those mostly at risk of PU development (Schoonhoven *et al.* 2002, Benbow 2008, Bales & Padwojski 2009). The study was conducted across 3 sites, capturing patients with neurological deficit, post-operative patients and the elderly population. Therefore PU prevention is an important concept for these patients (Schoonhoven *et al.* 2002, Benbow 2008, Bales & Padwojski 2009). Scheduling preliminary meetings with participants allowed for a rapport to develop and establish trust between the writer and participant. This led to participants being more relaxed and comfortable in the interview process which added value to the discourse of the interviews.

While the findings of this study have a number of strengths, it must be recognised that there are some limitations also. One of the main limitations was the time restraints in conducting this study. Primarily, this was caused as a result in the time delay in receiving ethical approval from the research ethics committee. Owing to a number of contributing factors, approval was not granted until late in December 2014, despite the original application submission in August 2014.

Consequently, recruitment and data collection did not commence until January 2015. As a result this shortened the time span available for data collection.

As there were 3 sites involved in this study, the writer found it challenging to alternate between each site. Scheduling preliminary meetings proved difficult as appointment times had to suit the potential participants as well as the gatekeeper or senior staff member providing the introduction. Some preliminary meetings were cancelled at the last minute owing to participant's unavailability to attend due to care needs. This transcended into the interview meeting times also. Therefore appointments required re-scheduling, some more than once. Additionally, as part of the recruitment phase, another 11 preliminary meetings took place across the sites with patients and carers. Arising from this, 5 individuals declined to take part in the study. The other 6 were unable to follow through to the interview phase due to their or their family members discharge home or transfer to another unit or to theatre. This necessitated further recruitment for the study. All of the aforementioned added to an already restricted timeframe.

While valuable information was retrieved from all study participants, the small sample size is perceived as a limitation to the study. The data obtained reflects the perceptions of only a small number of representatives across 3 sites within the regional quality improvement collaborative which overall had 21 participating sites. In addition, the small sample size of carers that participated within two of the three sites (acute and residential sites) is another limitation to this study and is attributed to unavailability of participants on the scheduled focus group appointment time. Also, while the 3 family members in the acute site contributed rich and valuable data to the study, they were all part of the same family. Consequently, their experiences were mostly attributed to one family member in the acute site. This is in contrast with that from the PCA where 4 different carers spoke of their experiences of 4 separate family members thus contributing a more varied account of their experiences. Because of the aforementioned reasons, the findings from this group, although relevant, may not be representative of all carers.

Another limitation to this study is the purposive sampling of participants. The gatekeeper was invaluable in identifying suitable participants for this study.

Purposive sampling has the capability to eliminate other potential individuals to participate in the research study (Silverman 2000). It must also be acknowledged that some contamination may have occurred as the participants that participated in the research may have spoken to each other about the study prior to being interviewed. Nevertheless, despite these limitations, the study findings will provide insight into the experiences of the study participants and are a useful starting point for developing knowledge in this area.

### **6.3 Implications of the Study Findings**

Ultimately, the goal of research is knowledge development (Caelli *et al.* 2003, Polit & Beck 2014). The patient and carer experiences of their involvement in a quality improvement collaborative on PU prevention utilising the SSKIN care bundle (Gibbons *et al.* 2006), has not previously been explored. As such, the findings of this study are invaluable to increase the knowledge base of all health care professionals and stakeholders involved in the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative and have meaning for further roll out of the collaborative.

#### **6.3.1 Implications for Collaborative Practice**

The findings of this study demonstrated that the majority of participants displayed a general lack of awareness and knowledge pertaining to the Pressure Ulcers to Zero (HSE 2013a) quality improvement collaborative. This indicates that these patients and carers may not have been informed of the initiative, nor were they invited to take part in collaborative activities. In addition, the findings of this study illustrate that participants had limited involvement in PU prevention interventions. Yet, patients and carers perspectives are fundamental in shaping the delivery of health services (HSE 2015, WHO 2015). While the rhetoric of engaging patients and carers in collaborative processes exists in the literature, it does not appear to be a reality in practice. Therefore there needs to be a change in current practices. The Model for Improvement framework which is composed of the Plan-Do-Study-Act cycle (IHI 2014), is taught in the collaborative learning process as an aid to structure sustained improvement (Evans *et al.* 2013). As such, it can be used among health care professionals as a means to continually explore and evaluate

new ways to engage and work with patients and carers in collaborative efforts and PU prevention interventions.

It is evident from the results of the regional phase of this collaborative that health care professionals have engaged in the quality improvement initiative. However there needs to be a shift in focus to include and engage patients and carers. This means that for future collaborative success, greater emphasis needs to be placed on creating awareness among patients and carers as well as health care professionals in the initial collaborative set up phase in each site. The findings of this study will illustrate to health care professionals that patients and carers want to be more involved in the collaborative process. Simply informing patients and carers of the sites involvement in a quality improvement collaborative and providing feedback of the collaborative results has the potential to elicit their interest and enthusiasm to engage. More importantly, the findings highlight how patients and carers expressed a desire to be more involved in their care or the care of their family member, with particular attention given to PU prevention. For these reasons, there needs to be a concerted effort by health care professionals to actively engage patients and carers in this quality improvement initiative as well as promote their involvement in PU prevention. One recommendation that requires consideration is the need to explore health care professionals and the collaborative MDT views and understanding on this concept.

Carers in particular, expressed an explicit wish to be more directly involved in the care of their family members. Providing carers with more responsibility in pressure area care could prove to be invaluable to patients and indeed the health care service. Carers are in regular attendance and are attuned to the preferences of those they care for. This could elicit further participation by patients through co-operation with their carers thus promoting earlier and timelier interventions. In turn, eliciting carers to perform simple PU prevention tasks, could serve as a potential to alleviate health care staff to attend to other duties. This should indeed be emphasized among collaborative teams. This may require individual organizations to devise new practice guidance with subsequent auditing to establish if this concept is beneficial to the organization. The PDSA cycle (IHI 2014) could again be utilised as a means to do so.



The results of this study's findings, exhibited how positive relationships between the health care professionals and patients and carers can empower individuals to participate in PU prevention. Capitalizing on partnerships such as these could make meaningful strides in engaging patients and carers in participation in PU prevention strategies. These partnerships could be accentuated more so in residential sites and PCAs, where patients are in the care of these health service areas for extended periods and appear more comfortable in their surroundings. As future collaborative teams will continue to be comprised of residential sites and PCAs this concept needs to be highlighted across this group set. This can be achieved during collaborative study days.

As PUs are seen as a key performance indicator of care quality, (Moore 2010, Foulkes 2011, Johansen *et al.* 2014) one recommendation would be to introduce the concept of patient engagement as a metric within the collaborative process. Foulkes (2011) defines a metric as a way of measuring the quality of healthcare. As such, the use of patient engagement as a metric could be twofold. Firstly, if used in combination with or as part of the SSKIN care bundle (Gibbons *et al.* 2006), it may serve as a guide for health care professionals to inform and involve patients and carers of PU prevention. Also, as a metric it could be used locally in participating sites to assess patients and carers experience of their involvement in the collaborative process and indeed PU prevention strategies. However before this can occur, health care professionals need to recognise and understand the inherent qualities patient and carer involvement brings to service design and healthcare delivery. Consequently, the value of patient and family-centered care approach needs to be accentuated across the collaborative roll out. Additionally, necessary education needs to be provided to health care professionals on how to engage and involve patients and carers in PU prevention.

### **6.3.2 Implications for Collaborative Management**

The findings demonstrated how the majority of participants believed the concept of the SSKIN care bundle (Gibbons *et al.* 2006) to be a good idea. However this was following much re-iteration on the writer's behalf of each element of the SSKIN acronym. Evident from the findings was the confusion that surrounded the

acronym SSKIN versus actual skin. Further confusion existed on the 'surface' element of SSKIN whereby some participants thought that it reflected the surface of the skin. This suggests that there lies a gap between what patients and carers understand of SSKIN compared to what health care professionals expect them to understand. While the acronym may be of benefit to health care professionals it raises the question of whether the acronym is suitably targeted towards patients and carers. It also questions the strength of using an acronym for alerting patients and carers on PU prevention strategies. In order for patients and carers to participate in PU prevention, they need to be able to understand the information being provided to them. As such, the findings of this study have identified how health literacy is fundamental to patient and carer engagement in PU prevention interventions. Therefore, all efforts to strengthen patient engagement should aim to improve health literacy. Some suggested recommendations include insuring patients and carers are involved in early collaborative activities which would assist in addressing issues such as this. Furthermore, involving patients or carers as part of the steering group of the Pressure Ulcers to Zero (HSE 2013a) collaborative may be an invaluable source of information and has the potential to keep patients/carers involved at all levels. Additionally sourcing feedback from patients and carers in the generation or production of any informational aids would provide rich viable data.

The results of the study by Gillespie *et al.* (2014) illustrated that service users were all able to re-iterate the 3 core messages of the PU prevention care bundle; 1.Keep moving 2.Care for your skin and 3.Ensure a good diet. While these results cannot be generalised owing to the small sample size of service users, it lends support to the findings of this study. Accordingly, adopting a more formal word process instead of an acronym as a care bundle approach, with fewer interventions, may elicit recall of preventative measures more readily for patients and carers. This approach may be more suited to those who displayed the most difficulty in understanding the acronym SSKIN, for example, those who identified themselves as illiterate and the elderly population. An important concept to remember among stakeholders is that PU development increases proportionally with age (Edsberg *et al.* 2014) and with the changing population demographic and the expected rise in the elderly population in Ireland, the incidence and prevalence

of PU is set to rise (Moore & Cowman 2011). Consequently, if the Pressure Ulcers to Zero (HSE 2013a) collaborative is to succeed on a national scale in its efforts in reducing overall incidence and prevalence rates of PUs, the health literacy needs among this vulnerable population group must be addressed. Henceforth, further research is warranted on this subject, comparing patients' and carers' preferences, understanding and participation on PU prevention using the acronym SSKIN against the use of a shorter, formal word process as a care bundle.

One of the findings of this study illustrated that only a minimal number of participants accredited an existence of the SSKIN care bundle (Gibbons *et al.* 2006). This was in part owing to the different collaborative techniques employed in each setting pertaining to PU prevention. If it is the continuing aim of the collaborative to utilise the SSKIN care bundle (Gibbons *et al.* 2006) in the quest to reduce the incidence and prevalence of PUs, it may be advisable that there is cohesion among participating collaborative sites to adopt this PU prevention care bundle strategy into practice. While it is important that individual sites adapt strategies suited to their needs and services, more emphasis may need to be placed on the role of the SSKIN care bundle (Gibbons *et al.* 2006) with advice given on its adaptation into practice. This could be provided at the collaborative training days. Inclusive of this information is the inherent need to emphasise each part of SSKIN equally. While not all aspects of the SSKIN care bundle (Gibbons *et al.* 2006) may be applicable to each individual, it has the potential to serve as a guide for future reference to individuals.

Another recommendation would be to accentuate on the preconceived ideas of participants within this study on PU prevention. For the most part, participants highlighted prevention as a key factor in pressure area care. Their use of the well known idiom, 'prevention is better than cure' could be utilised to assist in promoting PU prevention, as suggested by one participant. Additionally the majority of participants identified mobility as a key contributing factor to PU prevention. This may provide a basis from which to work in educating patients and carers in PU prevention strategies. Furthermore, skin inspection, surface and keep moving, were valued by the majority of participants as the most important elements from SSKIN in PU prevention. Conjoining these 3 key concepts within a bundle,

elaborating on skin care within skin inspection, could serve as a means from which to educate individuals on PU prevention. While incontinence and nutrition are also important aspects of PU prevention, they may not be applicable to all individuals.

A further aspect pertaining to the health literacy of individuals that requires attention stems from participants' range of denominations attributed to PUs as well as their comprehension of PUs and prevention interventions. This reflects the disparity in terminology used among different health care professionals and their use of medical jargon when communicating with these participants which is visible in the findings of the study. These findings indicate that patients and families may be at risk of misunderstanding health communications. An exemplar from the study's findings is when one participant believed a PU and a bedsore to be two different things. Therefore, if it is the fundamental aim to involve patients and carers in PU prevention it may be of benefit to standardise terminology for use in educating individuals. For example, agreement on the universal use of the term 'pressure ulcer' instead of 'bedsore'. The ideal would be to negotiate this among participating teams early in the collaborative training days.

The participants of this study offered some valuable insight into how they would prefer to receive information on PUs and PU prevention strategies. While verbal communication from healthcare professionals was considered the most preferential means, other avenues offered warrants consideration by collaborative teams and indeed by stakeholders of the Pressure Ulcers to Zero (HSE 2013a) collaborative. As it is the aim to embark on a national quality improvement initiative, there is some substantiating support provided by participants in this study on the effect that a national public campaign may bear on individuals. This suggestion should be further scoped and, if warranted, a national campaign should be considered through a partnership approach of national and professional agencies.

### **6.3.3 Implications for Education**

#### **6.3.3.1 Patient & Family/Carer Education**

One of the salient questions that has arisen from the findings of this research is at what point in the trajectory of their care should patients and carers be informed

and educated about the risk of PU development and the need for PU prevention interventions? While there were mixed views from participants on the subject, a consensus emerged that individuals should be told as soon as possible. The findings demonstrate that this sentiment takes precedence more so within the acute sites particularly among surgical patients. It is conceivable from the findings of the study that early communication in the trajectory of care will elicit both patients and carers understanding of PUs and participation in prevention techniques. Be that as it may, the findings also demonstrated that individuals must be ready to hear the message being conveyed to them. This finding needs to be imparted to health care professionals to promote the need for clinical judgement in providing this information to patients and carers. Further research is necessary on capturing the most influential time that information on PUs and PU prevention techniques should be given. With this in mind, it would have been very interesting to re-visit in the post operative phase, those pre-operative patients who declined to take part in this study to see if their opinions had changed. Indeed, further research exploring patients and carers perceptions on this topic in pre-operative stages and again post-operatively warrants consideration. In addition, exploring health care professionals views on this concept may add further insight.

The findings of this study illustrate how providing education to patients and carers is fundamental to their knowledge, shared decision making and participation in PU prevention strategies. While it was demonstrated that individuals may not be ready to hear the message being conveyed to them, clinical judgement by health care professionals is necessary. Timing of education requires tailoring to suit the needs of the individual. Bearing this in mind, one suggestion would be to emphasise among health care professionals involved in the collaborative, the need for re-iteration of information throughout the patients' trajectory of care. It suggests the need for written and verbal information to be provided recurrently. Indeed, this information should be provided both for the short term and long term in patients care. This is of particular importance for those patients with any neurological deficit.

The nurse was identified as the linchpin in providing forms of information on PUs and associated prevention interventions. However, varying emphasis was placed

on the remainder of the MDT team in the provision of similar information. Yet MDTs are endorsed in the literature on their role in pressure area care (Gould *et al.* 2000, Saliba *et al.* 2003, WOCN 2009, Jaul 2010, Moore *et al.* 2014a, Moore *et al.* 2014b) and indeed in the use of the SSKIN care bundle (Gibbons *et al.* 2006) (Resar *et al.* 2012, Whitlock 2013). If it is the ultimate aim to get PUs to zero, there needs to be a full team effort in all aspects of the initiative. With collaborative teams comprised of multidisciplinary members, increased emphasis needs to be placed on the role of each MDT member in providing education to patients and carers on PUs and associated self care prevention interventions. The collaborative training days will assist in conveying this message to all health care professionals.

### **6.3.3.2 Professional Education**

The findings illustrate the need for education to be provided to 'agency HCAs' in PU prevention. Indeed the carers in the PCA revealed that there was a stark contrast in knowledge with conflicting information provided to them among the 'agency' affiliated HCA's, who provided PU prevention interventions. With the expected directional shift in health care provisions from a hospital-based system to the home care setting (Probst *et al.* 2014), this is an important concept. If 'agency' HCAs are not adequately educated and trained in PU aetiology, detection and prevention techniques, the results could be detrimental for patients being nursed at home. It has been suggested that improving the knowledge base and the competencies of HCAs in PU prevention would improve quality of care (Hampton 2005). Therefore training needs to be provided in the prevention of PUs so that the 'agency' HCA is aware of any warning signs that pressure damage is occurring. Any planned endeavours to spread the collaborative needs to incorporate this into the program design and work in synergy with health care agencies to insure that those who provide care are educated in pressure area care. One recommendation would be to invite them to take part as participating teams in the collaborative training days.

From the findings a lack of available resources were identified in some sites, for example, limited staffing and unavailable equipment. Therefore there exists a need for health care professionals to utilise the resources available to them, to the best of their ability. Further emphasis could be placed on the latest evidence based

techniques in providing essential and effective care in PU prevention at collaborative training days. For example, facilitating health care professionals with education around use of the 30 degree repositioning technique (Moore & Cowman 2012), could assist in adapting this into the pattern of care they provide. This could enable health care professionals to develop skills in providing quick and easy repositioning with the least possible disturbance to the patient all the while adhering to evidence based practice (Victor 2013).

A rationale as to why participants were unaware of the SSKIN care bundle (Gibbons *et al.* 2006) is they may not have been told about it. While the presence of visual aids, for example the poster and information leaflets, did assist in creating awareness, these tools may be of limited value without the re-enforcement of verbal information by health care professionals. This stems from the participants' views where they would like to have been told about PU prevention and the SSKIN care bundle (Gibbons *et al.* 2006) as it would have allowed for a further discourse on the subject. In turn, this suggests that involving patients and carers through communication and shared decision making could have elicited their participation in PU prevention strategies.

From the evidence presented within this study, communication holds the key for the success of the Pressure Ulcers to Zero (HSE 2013a) collaborative. Therefore careful consideration needs to be given to this concept for future undertakings in the spread of the initiative. If it is the aim to engage and actively involve patients and carers in PU prevention, they must be effectively equipped with the necessary information to participate. Based on the recommendation provided by a participant within this study, communication as a 'two-way street' between health care professionals and patients and carers needs to be significantly emphasised among collaborative teams involved in the initiative. Utilising the Manojlovich *et al.* (2015) theory of communication involving 2 paradigms, could serve as an effective way to educate health care professionals on the importance of communication in this initiative. As evidenced within each theme and subthemes of the findings of this study, communication as a transactional process (responsible for information exchange) was lacking in some areas, thus impeding the transformational process (responsible for causing change). Ultimately this contributed to patients and carers

lack of awareness, knowledge and participation in PUs and associated prevention interventions. Conversely, where communication was provided on PU prevention through an effective transactional process, the results of the transformational process are evident in patients and carers knowledge and active engagement in care. Subsequently, communication as a 'two-way street' between health care professionals and patients and carers, plays a fundamental role in involving and engaging patients and carers as active participants in pressure area care. It allows health care professionals to provide education to individuals. For these reasons, educating health care professionals on this concept should be given priority as part of the collaborative process.

#### **6.4 Recommendations for Further Research**

The literature is devoid of patients and carers experiences of a quality improvement collaborative utilizing the SSKIN care bundle (Gibbons *et al.* 2006) in PU prevention. As such, the findings of this study have unearthed a number of research topics that require further research. Foremost is the need to explore the health care professionals experiences of the quality improvement collaborative initiative with a focus directed on patient and carer involvement. This could provide rich data to assist in determining their perceptions of involving patients and carers in PU prevention. Furthermore, based on the confusion surrounding SSKIN versus actual skin, the writer feels there is a need to explore patients and carers understanding and preferences on the use of an acronym compared to a word process care bundle. Addressing health literacy issues such as this could prove to be a determining factor in the success of patient and carer involvement in pressure area care and PU prevention strategies.

Additionally the appropriate timing of providing PU information to patients and carers warrants further research. This is most applicable to surgical sites within the acute care setting, where providing such information to patients and carers either pre-operatively or post-operatively could be comparably measured. Performing research on this topic inclusive of patients, carers and health care professionals could prove beneficial in earlier, timely PU prevention interventions. Finally, owing to the success of previous national advertising campaigns such as the 'QUIT' smoking campaign (HSE 2013d) and indeed the hand hygiene campaigns lends



support to devising a public awareness campaign on PU risks and prevention techniques. A larger scale exploration on patients and carers perception of this idea is warranted. Conducting further research on the aforementioned topics could prove most beneficial in reducing pressure ulcers to zero.

### **6.5 Dissemination of Findings**

Gathering information to gain new knowledge is not a useful activity if no one learns about it (Rebar *et al.* 2011). Therefore an important obligation of any researcher is to share and communicate the research findings, especially if the research has the potential to impact on patient care quality (Creswell 2007). With this in mind, the writer plans to disseminate the findings of the study to the Directors of Nursing and health care professionals at each site that took part in this study. A report on the findings will be compiled and presented to the Pressure Ulcers to Zero (HSE 2013a) collaborative steering group to assist in their spread of the initiative. A meeting was already held in June 2015 with key stakeholders planning the national roll out of the Pressure Ulcers to Zero (HSE 2013a) collaborative. It is hoped that the writer will assist in disseminating these findings to future prospective collaborative team participants. In addition a report will be provided to the Nursing and Midwifery Practice Development Unit in the Dublin North East who funded the research.

A copy of this thesis will be submitted to the library of the Royal College of Surgeons in Ireland and, as requested to the research ethics committees and the hospital library to which the writer is affiliated, as requested by the Director of Nursing. In addition, it is aimed to present and publish the findings in relevant national and international conferences and journals. As such, the writer has successfully submitted an abstract to the European Pressure Ulcer Advisory Panel (EPUAP) International Conference 2015 and has been invited to participate in a poster presentation of the research findings.

### **6.6 Personal Reflections of this Study**

The concept of reflection is propounded within the literature as an epistemology for practice that allows practitioners to solve their daily problematic situations through conscious thought processes which in turn leads to practice-based knowledge

(Jasper 2001, Oelfsen 2012). Furthermore, engaging in regular reflection enables health care professionals to manage the personal and professional impact of addressing their patients' health and wellbeing needs on a daily basis (Oelfsen 2012).

Throughout the research process, I maintained a reflective journal which I found to be invaluable. It allowed me to reflect on thoughts and incidents that occurred on a day to day basis throughout the research journey. Overall, as a novice researcher, this study increased my understanding and knowledge of the research process. I experienced recurrent feelings of frustration with the time delays that occurred as a result of the ethics application process. Additionally I was utterly daunted by the prospect of the interviews, and, even more so, the focus groups. The pilot interview therefore served as an invaluable learning experience, as it identified the areas that I needed to improve on before proceeding with the other interviews. The journal shows that my confidence increased following each interview, with the quality of the data collected also improving on each interview and focus group. This in turn increased the richness of the data. Also, I was not prepared for the magnitude of data collected. Owing to the 25 lengthy transcripts which totalled over 122,000 words, data analysis was more time consuming than I originally envisaged.

Nevertheless, I thoroughly enjoyed the research experience. Indeed there are some parts of the journey that stand out more than others. One such experience was meeting the different participants in the preliminary meetings. These initial meetings allowed me openly speak with individuals and develop a rapport with them of which she utterly enjoyed. Additionally the writer firmly believes that this contributed to participants being more relaxed and comfortable during the interviews and focus groups. Furthermore, participants expressed that being involved in the study was a positive experience for them as it allowed them to discuss relevant issues which they hoped would in turn help others. Subsequently as their advocate the writer feels that she has given a voice to the unspoken. The writer feels privileged to have been given the unique opportunity of sharing the experiences of the participants involved in this study. Coming to the end of the research journey, the writer feels a sense of satisfaction with the belief that new

knowledge will be gained from the patient and carers experiences of their involvement in a quality improvement collaborative utilizing the SSKIN care bundle (Gibbons *et al.* 2006) in PU prevention. I am a firm advocate for nurses to continue their professional development therefore I was very grateful for the opportunity presented to me to enhance my knowledge and academic portfolio. Although excited to return to academic studies, I was also nervous at the prospect of executing such an undertaking. However my worries were short lived owing to the excellent guidance and encouragement from my academic supervisors. As a novice researcher I felt fully supported and mentored which has helped me to advance in each stage of the research process. Furthermore I found the tutorials provided by the lecturers to be hugely beneficial in planning and completing the different stages of my research endeavour. The relationships that I developed amongst my post graduate colleagues have been an invaluable strength to aid me in getting to where I am today. The group meetings that we shared with each of our supervisors provided further insight and offered us to explore and learn about other avenues of research. Overall I have thoroughly enjoyed my time as both a post graduate student and a researcher.

## **6.7 Conclusion**

The findings of this study provide a unique contribution to understanding patients' and carers' experiences and involvement within a quality improvement collaborative including use of the SSKIN care bundle in the PU prevention. As part of the Pressure Ulcers to Zero (HSE 2013a) collaborative initiative, it was envisaged that a patient and carer centred approach be adopted by collaborative teams to improve healthcare methods in relation to PU prevention using the SSKIN care bundle (Gibbons *et al.* 2006). Overall the findings of the study suggest that both patients and carers had limited awareness and involvement in the collaborative initiative. Further, a general lack of awareness of the SSKIN care bundle (Gibbons *et al.* 2006) was identified, with involvement in PU prevention fragmented across the settings. As such the rhetoric of patient awareness and engagement in collaborative planning and activities identified within the quality improvement literature, does not appear to be a reality in practice. Yet participants expressed the desire to be more involved in the collaborative and indeed PU prevention interventions. Consequently changing practices need to be encouraged

and implemented to engage patients and carers to assume a more active role in shared decision making and self care in PU prevention strategies, as this will yield better outcomes for the patient and the health service.

The findings of the study identified significant barriers, such as knowledge and health literacy among patients and carers. Accordingly there must be a concerted effort from all MDT members to work in synergy in providing education to patients and carers. Providing education through both verbal and written information at a level that patients and carers can understand is fundamental to the avoidance of PUs. This signals the need for all collaborative stakeholders to address the health literacy needs among patients and carers. This has meaning for future collaborative success, where tools, such as acronyms and activities, for example the design and presentation of visual aids pertaining to the collaborative subject, require a patient as well as a professional focus.

If an overall reduction of 73% of avoidable PUs can be accomplished within this quality improvement collaborative with minimal patient and carer involvement, a greater reduction could be achieved if patients and carers are fully informed and participate in care practices and overall collaborative strategies. Empowering patients and carers through education and communication as a 'two way street' is vital for their participation in pressure area care and associated PU prevention interventions. Ultimately, this holds the key for future collaborative success in attaining a goal of getting 'Pressure Ulcers to Zero' (HSE 2013a).

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# **Appendices**

**Appendix1**

**Ethical approval from the Local  
Research Ethics Committee**

Ms \*\*\*\*\*  
Director of Nursing  
\*\*\*\*\* Hospital  
\*\*\*\*\*  
\*\*\*\*\*

18<sup>th</sup> December 2014

Our Ref: 1137811672

RE: An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative Research Proposal, Version 5: 2014  
Participant Information Sheet for Patients, Version 6: 2014  
Consent Form for Patients, Version 5: 2014  
Participant Information Sheet for Relatives / Carers, Version 5: 2014  
Relative or Carer Consent Form, Version 5: 2014  
Letter to the Director of Nursing, 4<sup>th</sup> November 2014, Version 5: 2014  
Letter to the Clinical Nurse Manager, 4<sup>th</sup> November 2014, Version 5: 2014

Dear \*\*\*\*\*  
(Principal Investigator)\*\*\*\*\*

I acknowledge receipt of your correspondence dated 15<sup>th</sup> December 2014 enclosing revised Participant Information Sheet for Patients (Version 6: 2014), revised Consent Form for Patients (Version 5: 2014), revised Participant Information Sheet for Relatives / Carers (Version 5: 2014) and revised Relative or Carer Consent Form (Version 5: 2014) for the above research study to be carried out at \*\*\*\*\*

This correspondence has been noted and the revised documents have been approved. Approval to proceed with this research study at the \*\*\*\*\* is granted; this approval is valid until 22nd October 2016.

It is your responsibility to adhere to the approved study protocol and ensure that all investigators involved with the research only use the approved documents without deviation (unless they have been approved by the Research Ethics Committee), to submit annual reports setting out the progress of the research (giving details of the number of participants who have been recruited, the number who have completed the study and details of any adverse events etc.) and to notify the Research Ethics Committee when the research is concluded.

The \*\*\*\*\* Research Ethics Committee would like to remind all investigators involved in research of their legal obligations under the law on Data Protection.

Yours sincerely

---

Chairman  
Research Ethics Committee

c.c. Ms Emma Fleming, Clinical Nurse Manager I,

\*\*\*\*\* (Principal Investigator- as per the REC guidelines, any individual who wishes to conduct piece of research within the site must have a senior representative as the principal investigator)

**Appendix2**

**Approval from the Primary Care  
Research Ethics Committee**



Sent Items

Tuesday, December 23, 2014 10:44 AM

Dear Mary,

Many thanks for your email. I appreciate your assistance in the matter. I look forward to collecting the data early in the new year.

Kind Regards,

Emma Fleming  
MSc by Research Student, RCSI  
(086) 1679839  
email: emmaflaming@rcsi.ie

To: Emma Fleming

Cc: Keane, Shirley - National PCT Programme [shirley.keane@hse.ie];

Inbox Monday, December 22, 2014 2:26 PM

You replied on 12/23/2014 10:44 AM.

Dear Emma

Thank you for your email which I will deal with Shirley's absence. I have read the attached documents. You have provided the clarity requested by the committee and evidence of Ethical approval. Therefore your application is approved. I wish you every success in your research and look forward to the publication.

Regards

Mary

(Chair of Primary Care Research Committee)

Mary Wynne

Area Director Nursing and Midwifery Planning and Development DNE

HSE Mill Lane

Palmerstown

Dublin 20

email: mary.wynne1@hse.ie

Mobile: \*\*\*\*\*

**From:** Emma Fleming [mailto:emmaflaming@rcsi.ie]

**Sent:** 22 December 2014 12:53

**To:** Mary Wynne

**Subject:** FW: Ethics Application documentation - An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.

Dear Mary,

Re: An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.

I refer to the above research application to the Primary Care Research Committee which was considered at their meeting on the 16/10/2014 (please refer to the email below from Ms. Shirley Keane)

Please see attached the approval letter from the \*\*\*\*\* Research Ethics Committee to proceed with the research study. Also attached is my response letter to the Primary Care Research Committee's recommendations as well as all of the revised documents.

Should you have any further questions, my contact details are outlined below.

I appreciate the Primary Care Research Committee's time and expertise in reviewing my application.

Many thanks for your assistance in this matter.

Kind regards,

Emma Fleming

Msc by Research, RCSI  
(086) 1679839 (personal mobile)  
(085) 8727337 (work mobile)  
Email: emmafleming@rcsi.ie  
**Emma Fleming**

**RCSI MSc Nursing 14-15**  
Royal College of Surgeons in Ireland

Subject: Ethics Application documentation - An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.

Date: Mon, 27 Oct 2014 18:07:55 +0000

From: shirley.keane@hse.ie

To: e.fleming@live.ie

CC: mary.wynne1@hse.ie

Dear Emma,

I refer to your Research Application to the Primary Care Research Committee. This was considered at their meeting of the 16/10/2014 last and their decision was as follows:

**Emma Fleming – An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.**

- \*\*\*\*\* is the only part of this application that is within scope of PCRC.
- Section C1.3 - Seeking PHNs to do the recruitment within 24-48 consideration period (cooling off period) for participants – concern over this time period.
- Appendix 9 – Proposed one to one interview schedule (for patients) – discussed and subsequently clarity requested on first question.
- Key issue – are we happy that the PHNs will act as recruiter for participants for this project – further to discussion this was agreed as being in order.
- Ensure that those participants in focus groups are clear that patient confidentiality is respected.
- Observation 3.1 and 5.7 – observation that there is a contradiction but as these patients are probably within a different setting not within PCRC

***Decision: Approved subject to clarity on the above and submission of ethical approval***

Kind regards,

Shirley Keane,

On behalf of Chair, Primary Care Research Committee.

**Shirley Keane,**

**Business Planning and Development Manager,**

**Office of Head of Planning, Performance and Programme Management,**

**Primary Care Division.**

**From:** emma fleming [mailto:e.fleming@live.ie]

**Sent:** 06 October 2014 14:48

**To:** Keane, Shirley - National PCT Programme

**Subject:** Ethics Application documentation

Hi Shirley,

Please find attached all the relevant documentation to date for the Research Ethics Committee. I have applied for Ethical approval from the Research Ethics Committee within the \*\*\*\*\* Hospital and I will be attending their hearing date on 22nd October.

Included in the attachments are: Standard Application Form, Narrative Summary, Research Proposal, Appendix 1-10.

If you have any questions or if I am missing anything that you think I may need for the Primary Care Ethics panel please do not hesitate to contact me.

Kind Regards,

Emma Fleming

MSc by Research Student RCSI

(086)1679839

Email: [e.fleming@live.ie](mailto:e.fleming@live.ie)

or : [emmafleming@rcsi.ie](mailto:emmafleming@rcsi.ie)

**Appendix3**

**Ethical approval from the**

**RCSI Research Ethics Committee**

The Royal College of Surgeons in Ireland  
The Research Ethics Committee  
121 St. Stephens Green, Dublin 2, Ireland.  
Tel: +353 1 4022205 Email: recadmin@rcsi.ie

Dr David Smith, Acting Chair  
Dr Niamh Clarke, Convenor  
in January 2015

Ms Emma Fleming  
HSE Dublin North  
Swords Business Campus  
Balheary Road  
Swords, Co. Dublin

Ethics Reference No:	N/A (accepted from ***** Hospital)
Project Title:	An exploration of the patient and family / carer experience, of the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.
Researchers Name (lead applicant):	Ms Emma Fleming
Principal investigator on the project (PI):	Ms ***** Director of Nursing
Other Individuals Involved:	Academic supervisors: Professor Zena Moore, School of Nursing, RCSI and Dr. Sarah Condell, former Nursing and Midwifery Research & Development Lead in the ONMSD HSE

Dear Ms Fleming

Thank you for your Research Ethics Committee (REC) application. The RCSI HREC accepts the ethical approval granted by the \*\*\*\*\* Hospital REC for the research study (details above) submitted by Ms Emma Fleming.

This letter provides approval for data collection for the time requested in your application and for an additional 6 months. This is to allow for any unexpected delays in proceeding with data collection. Therefore this research ethics approval will expire on 7<sup>th</sup> **July 2016**

Where data collection is necessary beyond this point, approval for an extension must be sought from the Research Ethics Committee.

This ethical approval is given on the understanding that:

- All personnel listed in the approved application have read, understand and are thoroughly familiar with all aspects of the study.
- Any significant change which occurs in connection with this study and/or which may alter its ethical consideration must be reported immediately to the REC, and an ethical

amendment submitted where appropriate.

- Please submit a final report to the REC upon completion of your project.

We wish you all the best with your research.

Yours sincerely,

*AJ*

*- 1 ?*

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PP Dr Niamh Clarke (Convenor)

Dr David Smith (Acting Chair)

## **Appendix 4**

### **Letter to the Director of Nursing**

Ms. \*\*\*\*\*,  
Director of Nursing  
\*\*\*\*\* Hospital / Care Area  
\*\*\*\*\*

Dublin.

*Re: A research study to explore the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.*

Dear\*\*\*\*\*,

I am presently undertaking an MSc by Research at the Royal College of Surgeons in Ireland by conducting the above research study. My supervisors for this work are Professor Zena Moore, RCSI (the well published Irish expert in the area) and Dr Sarah Condell (Former Nursing and Midwifery Research and Development lead in the ONMSD HSE).

As .....(hospital / ward/ unit/ care area) has been a lead ward/ unit/ care area partaking in the HSE Dublin North East 'Pressure Ulcers to Zero' Quality Improvement Collaborative, I would like to propose that part of the data collection for this study be obtained from here.

The aim of the proposed research is to explore the patient and family or carer experience of implementing the **SSKIN** care bundle (which aims to prevent pressure ulcers) within a regional quality improvement collaborative. This is an important research of concern to nursing as it will inform the patient-centeredness element of the quality improvement collaborative into the future.

I am writing to you to seek your permission to gain access to your hospital /care area and proceed with this study. To conduct this research, I must recruit eligible participants using a purposive sampling method of selection, with data collection obtained in the form of semi-structured digital voice recorded interviews (for patients) and focus groups (for relatives / carers). For this to occur, I hope to identify suitable participants that meet eligibility criteria with assistance from the Clinical Nurse Manager of the lead ward /unit partaking in the 'Pressure Ulcers to Zero' quality improvement collaborative. If agreeable, I would like to request that the Clinical Nurse Manager then approaches the potential participants, seek their willingness to volunteer to participate in the study and request their permission for their name to be given to me, the researcher. Once the participant is agreeable, I will then approach the prospective participants and using a specifically designed participant information leaflet, I will inform those identified and seek their consent to participate in the study.

Ethical approval has been granted from the local Research Ethics Committee. I assure you that complete anonymity and confidentiality of the participants and the institution will be protected at all times. Furthermore, any future publication of the research findings will not identify the participants or the organisation in any way. I would be most grateful for your permission to conduct this research. I enclose a copy of the research proposal for your convenience.

Should you require any additional information, please do not hesitate to contact me.

Yours sincerely

---

Emma Fleming



MSc by Research student RCSI  
PG Dip Wound Care & Tissue Viability,  
Dip First Line Management, RGN.  
Telephone: \*\*\*\*\*  
Email: [emmafleming@rcsi.ie](mailto:emmafleming@rcsi.ie)



**RCSI**



**Appendix 5**  
**Approval from the Director of Nursing**  
**Acute Site**

173-\*\*-bd-15

16 January 2015

Emma Fleming  
Msc by Research Student, RCSI.  
NMPDU HSE Dublin North  
Swords Business Campus  
Balheary Road  
Swords  
Co. Dublin

Dear Emma,

I refer to your correspondence of 22, December 2014 seeking permission to carry out your research project in the  
\*\*\*\*\*

I am delighted to facilitate your request and may I wish you well with your studies and hope that on completion of your course, you will make a copy of your thesis available to the CNE library.

Kind regards,

---

\*\*\*\*\*

**Director of Nursing**

**Appendix 6**

**Approval from the Director of Nursing**

**Primary Care Area**

Emma Fleming Actions In response to the message from \*\*\*\*\*, 1/2/2015

To:\*\*\*\*\*

Attachments:

RCSI-Logo.png (11 KB)

Sent Items

Monday, January 05, 2015 9:43 AM

Many thanks \*\*\*\*\*.

I appreciate your assistance and best wishes. I will liase with \*\*\*\*\* TVN CNS and with \*\*\*\*\* PHN  
\*\*\*\*\*, with whom I have spoken previously.

I look forward to my time in the \*\*\*\*\* area.

Kind regards,  
Emma Fleming

Actions

To:Emma Fleming

Cc: \*\*\*\*\*

Inbox Friday, January 02, 2015 4:35 PM

You replied on 1/5/2015 9:43 AM.

Dear Emma,  
Thank you for your reply.  
I have informed \*\*\*\*\* that you will be in contact with her.

You will appreciate that the Community Nursing team do not have the capacity to do extra visits to  
the patients you will identify for your study.

Good luck for 2015,  
Kind Regards,

\*\*\*\*\*

*Director PHN.*  
*Primary, Community & Continuing Care*  
*\*\*\*\*\* Dublin North*  
*\*\*\*\*\* Health Centre*  
\*\*\*\*\*

[Emma Fleming](#)

ActionsTo:~\*\*\*\*\*

Sent Items

Friday, January 02, 2015 2:56 PM

Dear Ms. \*\*\*\*\*,

I hope you enjoyed the holidays. Foremost I would like to thank you for your response to my  
previous email.

I would also like thank you for your concern for the rigour of the study, however the issue has  
already been discussed at the two research ethics committees (acute hospital and primary care),

who were satisfied that the CNM or PHN would select patients as this is an exploratory, qualitative study to understand the patients and client experience of the collaborative. Any biases that such selection brings will be made explicit in the research report. However, I am very willing to contact and speak with Ms. \*\*\*\*\* (TVN CNS) regarding the study. I would be much obliged if you could forward her email address onto me.

Regarding the issue of dementia, as per the inclusion criteria all patients must be able to give an informed consent. It may occur that potential candidates level of capacity may be in question. Therefore the researcher will liaise closely with the CNM or PHN to ensure that those potential patient participants selected, do indeed have the capacity to sign and give an informed consent. The CNM or PHN patient participation selection has the potential to avoid this issue.

I hope this information helps. Please do not hesitate to contact me should you have any further queries.

Kind Regards,

Emma Fleming  
MSc by Research, RCSI  
HSE Dublin North  
Swords Business Campus  
Balheary Road  
Swords  
Co. Dublin  
Phone: (085) 8727337 (work mobile)  
Email: emmaflaming@rcsi.ie

From: \*\*\*\*\*>]  
Sent: Wednesday, December 24, 2014 1:12 PM  
To: Emma Fleming  
Subject: RE: Research Study- Pressure Ulcers to Zero

Dear Emma,

Thank you for your information.

I have some questions on your proposal which will require clarification.

Are you planning to do random sampling for a number of clients in the \*\*\*\*\* (PCA)?

If the PHN chooses the clients this will influence the outcomes. I would question the ethics of a PHN choosing your client group.

I would recommend that you forward invitations to the clients independently, select a percentage for a scientific research.

How will you differentiate between client and carer where there may be a level of dementia present. Have you considered seeking assistance from \*\*\*\*\* CNS Tissue viability who was involved in the collaborative?

The crucial point here Emma is that your research must be independent and impartial therefore avoiding any influence on the outcome if nurses known to the patients are involved,

Kind Regards,

\*\*\*\*\*

Director PHN.  
Primary, Community & Continuing Care

---

From: Emma Fleming [<mailto:emmaflaming@rcsi.ie><<mailto:emmaflaming@rcsi.ie>>]

Sent: 23 December 2014 10:29

To: \*\*\*\*\*

Subject: Research Study- Pressure Ulcers to Zero

Dear Ms. \*\*\*\*\*,

Re: An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.

Foremost, I wish to relay my sincerest appreciation for your assistance in conducting this valuable piece of research in the \*\*\*\*\* Primary Care Area. Following a long process I have received ethical clearance from the \*\*\*\*\* Research Ethics Committee to proceed with the study. I have also been granted permission to proceed with the study in the \*\*\*\*\* area, from the Primary Care Research Committee DNE.

Please see attached my official request seeking permission to carry out the data collection for the above research within the \*\*\*\*\* area (a hard copy of the letter is also in the post). Also attached is a copy of the Research Proposal.

I hope to commence data collection early in the new year. I have previously linked with \*\*\*\*\*PHN in \*\*\*\*\* Health Centre. Once I receive your response I will finalise suitable dates and appointment times with \*\*\*\*\* to proceed with the data collection from the patients and families/ carers.

Should you have any further questions, my contact details are outlined below.

Once again, many thanks for your assistance. I hope you have a lovely Christmas and that you enjoy the holidays!

Kind regards,

Emma Fleming  
MSc by Research, RCSI  
HSE Dublin North  
NMPDU  
Swords Business Campus  
Balheary Road Swords Co. Dublin  
Phone: (086) 1679839 (personal mobile)  
(085) 8727337 (work mobile)  
Email: emmaflaming@rcsi.ie <<mailto:emmaflaming@rcsi.ie>>

Emma Fleming

**Appendix7**

**Approval from the Director of Nursing**

**Residential Site**





Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

6 January 2015

Ms. E. Fleming  
MSc by Research student RCSI  
PG Dip Wound Care & Tissue Viability  
Dip First Line Management, RGN.

HSE Dublin North  
Swords Business Campus  
Balheary Road  
Swords  
Co. Dublin

Re: A research study to explore the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.

Dear Emma

Further to your letter dated 22nd December 2014. I am happy to grant permission to you to conduct this research in \*\*\*\*\*  
Wishing you all the best

in your studies.

Regards

---

Director of Nursing  
\*\*\*\*\*

## **Appendix 8**

### **Letter to the Clinical Nurse Manager**

Ms. \*\*\*\*\*

Clinical Nurse Manager ,

\*\*\*\*\*,

Dublin .

15<sup>th</sup> December 2014

Re: *A research study to explore the patient and family or carer experience of implementing a pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.*

Dear \*\*\*\*\*,

I am presently undertaking an MSc by Research at the Royal College of Surgeons in Ireland by conducting the above research study. My supervisors for this work are Professor Zena Moore, RCSI (the well published Irish expert in the area) and Dr Sarah Condell (Former Nursing and Midwifery Research and Development Lead in the ONMSD HSE). The aim of the proposed research is to explore the patient and family or carer experience of implementing the **SSKIN** care bundle within a regional quality improvement collaborative. This is an important research of concern to nursing as it that will inform the patient-centeredness element of the quality improvement collaborative into the future. I am currently seeking permission from the Hospital Research Ethics Committee to proceed with this study.

As \*\*\*\*\* (Ward / Unit ) has been the lead ward / unit/ partaking in the 'Pressure Ulcers to Zero' quality improvement collaborative within the \*\*\*\*\* (.....Hospital / care area) I would like to propose that data collection for this study is obtained from your ward/ unit/ care area. All participants will be given a full explanation of the proposed research study using a specifically designed information sheet and will also be given the opportunity to ask questions of the researcher so that they can choose if they wish to participate or not. If they do agree, an informed, written consent will be obtained prior to commencing data collection. The anonymity of the organisation, the ward/unit/ care area and all participants will be maintained throughout the study.

To conduct this research, I must recruit participants using a purposive sampling method of selection. The collection of data will be through the use of digital voice recordings, in the form of

1.semi-structured, individual patient interviews, comprising of 3 to 6 patients

2.family / carer focus groups, comprising of 4 to 6 candidates.

For this to occur, I will require your assistance in identifying potential participants who fit the following criteria.

Inclusion criteria:

- Patients (or the family member / carer of patients) that are receiving care (or have received care) in your ward / unit/care area that is participating in the 'Pressure Ulcers to Zero' Quality Improvement Collaborative.
- Patients (or the family member / carer of patients) are receiving care (or have received care) as per the **SSKIN** bundle of care for the prevention for pressure ulcers.
- Participants included are adults (i.e. over 18 years of age).
- Participants are able to sign an informed consent to be involved in the study, knowing that during the interview they would be expected to express their thoughts and feelings about their experiences.
- Participants are able to speak English

Exclusion criteria:

- Failure to meet any of the above inclusion criteria.
- Patients that are pregnant.

Following selection of the candidates, I would be much obliged and if it is agreeable with you, that you will then approach these potential participants, seek their willingness to volunteer to participate in the study and request their permission for their name to be given to me, the researcher. Once the participant is agreeable, I will then approach the prospective participants and using a specifically designed participant information leaflet, I will inform those identified and seek their consent to participate in the study.

I assure you that complete anonymity and confidentiality of the participants, ward/ unit and the institution will be protected at all times. Data will be collected using digital voice recordings and will be transcribed immediately after. All identifiable personal details of participants will be erased. The data will be stored in a secure password operated hardware. My academic supervisors and I will be the only persons with access to this data. Furthermore, any future publication of the research findings will not identify the participants or the organisation in any way.

In the highly, unlikely event that during the collection of data, the participant experiences some distress if issues are raised, or incidents are recalled that may have been upsetting to them, I am asking for your assistance in relation to supporting the participants and directing them to the appropriate support pathway.

I would be most grateful for your assistance in conducting this research. I enclose a copy of the research proposal for your convenience and I will be happy to answer any queries you may have about the study.

I look forward to hearing from you.

Kind regards,

---

Emma Fleming.

MSc by Research Student RCSI.  
RGN, PG Dip Wound Care & Tissue Viability,  
Dip First Line Management.

Telephone: \*\*\*\*\*

Email: emmafleming@rcsi.ie



RCSI



## **Appendix9**

### **Participant Information sheet for patients**



You are being invited to take part in a research study. This information sheet explains why the research is being done and what it would involve for you. This will help you decide if you want to volunteer to take part. Please take the time to read this information carefully and speak to others about the study if this would help.

### **The Research Study:**

The title of the study is: ***'An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.'***

The study is being conducted for a Masters by Research award and is being supervised by Professor Zena Moore of the Royal College of Surgeons in Ireland and by Dr Sarah Condell, former Nursing and Midwifery Research and Development Lead, ONMSD, HSE.

### **What is the purpose of this study?**

Pressure ulcers, more commonly known as pressure sores or bedsores, are areas of skin damage, usually over a bony area (e.g. elbows, buttocks, heels), which happens when pressure is applied to that area for a long period of time. The purpose of this study is to explore how patients, being cared for with a 'bundle of care' to avoid a pressure sore developing, find that experience.

### **What is the bundle of care?**

The 'bundle of care' or the set of preventative measures that are used are known as:

#### **SSKIN**

**Skin inspection:** early inspection means early detection! Skin inspection should be carried out regularly and any areas of redness, tenderness, soreness, areas of broken skin including blisters, especially over bony areas should be monitored closely.

**Surface:** Make sure you have the right support. Based on your skin inspection you may require special equipment such as a mattress or cushion to reduce the pressure in particular places. Ensure your clothing / bedding is not creased and that any tubing, call bells or mobile phones are not under your body causing damage to your skin.

**Keep Moving:** Active movement and changing your position frequently is advised. If feasible, mobilise regularly.

**Increased moisture to the skin or Incontinence:** Make sure your skin is clean and dry. Ensure skin and clothing is not damp from excess moisture such as sweat or urine.

**Nutrition & hydration:** If feasible and if allowed by your medical team, eating a healthy balanced diet and drinking plenty of fluids is recommended.

### **Why have I been chosen?**

You have been asked to take part because you are being (have been) cared for within the \*\*\*\*\* Primary Care Area, by a team who want to learn from their practice and improve the care they deliver. The team taking care of you have been part of a quality improvement collaborative project entitled 'Pressure Ulcers to Zero' within the HSE in the Dublin North East area, which aims to reduce the number of pressure ulcers from occurring by using the 5 elements of the SSKIN care bundle, as listed above.

**Do I have to take part?**

Taking part in this study is entirely your decision. If you choose not to take part this will be respected and will not affect your care in any way. If you do decide to take part you will be asked to sign a consent form before being involved in any activities.

**What will happen during the study?**

If you decide to take part you will be invited to speak with the nurse researcher involved in the study about how you found the care that you are receiving (or have received) relating to pressure ulcer prevention. You will have the opportunity to talk about your experiences of the SSKIN care bundle, what is easy or difficult, what is important to you and what would improve your experience. With your agreement, the interview will be digitally voice recorded to ensure that your story is accurately captured. The interview will take place over a period of approximately 45 minutes. The location of the interview will depend on the facilities available on site and patient preference. This may include the patient bedside, in a designated day room or the patients own home. If at any stage you want to stop the interview for any reason you may do so.

**Will my information be kept confidential?**

If you agree to take part in this study, every effort will be made to maintain confidentiality of your personal details. So, for example, your name and any personal information revealed during the interview will be given a number or other term so that you cannot be identified in any way and no personal information will be traced back to you. The digital voice recorded interview will be transcribed directly after the interview. Your name will not be included in the transcript. The transcript of the interview will be stored in a secure password operated hardware system, of which the researcher is the only person with access. The only people who may see the transcripts will be the researcher and her supervisor(s) in the Royal College of Surgeons in Ireland. We can make arrangements for you to see the transcript, should you wish to do so. In the final report of the study, anonymous quotes will be used to support the findings. Any future publication of the research findings will not identify you, the unit or the healthcare organisation in any way.

**What happens to the information after the study?**

The interview transcripts, with the information you have provided, will be retained for a period of up to 5 years. This information will be stored on a secure password operated server located in the Royal College of Surgeons in Ireland (RCSI) building in Dublin. This is to allow access to information should further research in the area be indicated. There is no intention to re-use the information once the final analysis of the study has occurred. However, should the need arise to re-visit the research information, approval will be sought from the Research Ethics Committee, prior to any further research being conducted.

Following the 5 year time frame, all of the information will be destroyed when no longer of use to the study. All information will be handled and stored in accordance with the requirements of the Data Protection Act 2003.

**The possible benefits of the study:**

The information obtained from this study will assist nurses and carers to gain a greater understanding of the importance of the prevention of pressure ulcers using the 5 elements of the SSKIN care bundle, and in particular the patients' role in that bundle of care. This in turn will allow for a greater quality of care for future patients. It is hoped that the findings of this study will assist when the SSKIN care bundle is used in other wards, units or hospitals outside of the Dublin North East Region.

You may also find that participation in this study is of benefit to you, as it will give you the opportunity to talk about issues you have regarding this subject.

**The possible risks of this study:**

In the unlikely event that during the interview, you find that issues raised or incidents recalled upset you, the interview will be stopped. The researcher will liaise with the Public Health Nurse, in relation to appropriate supports for you. In some instances your Medical Team /GP may need to be consulted.

In the interest of patient / client safety, if you report an area of poor or dangerous practice, I will need to speak with the relevant senior nurse manager from the area so that action can be taken to prevent similar situations from occurring in the future. Also, if I detect from any discussions with you that you are at risk of harming yourself or others, I have a duty of care to discuss my concerns with the relevant professional staff in order to ensure that appropriate care or support is provided.

**May I refuse to take part or withdraw from the study?**

Yes, you may refuse to take part in the study or withdraw from the study at any time, without giving a reason. Should you do so, this decision will be respected and will not affect your care in any way.

**What will happen to the results of the research study?**

The results of this study will help to improve practice and the quality of care relating to the patients involvement in pressure ulcer prevention and in particular to the SSKIN bundle of care. The findings will be presented in a dissertation and will be sent for publication in a professional journal and / or presented at conferences.

**Permission:**

I have been granted ethical approval from the \*\*\*\*\*Research Ethics Committee, the Royal College of Surgeons Research Ethics Committee and the Primary Care Research Committee Dublin North East, to proceed with this study. I have also obtained permission from the relevant people such as the Director of Nursing and the Public Health Nurses to conduct this study within the \*\*\*\*\* Primary Care Area.

**Further Information and Contact Details:**

If you have any queries or would like further information on the study, please ask the nurse to contact me. I will arrange to speak to you at a time that suits you. My contact details are as follows:

**Researcher:**

---

Emma Fleming.

MSc by Research Student RCSI  
RGN, PG Dip Wound Care & Tissue Viability,  
Dip First Line Management.

NMPDU HSE Dublin North  
Swords Business Campus  
Balheary Road  
Swords  
Co Dublin  
Telephone: \*\*\*\*\*  
Email: emmafleming@rcsi.ie





Thank you for taking the time to read this information.



**Appendix 10**

**Participant Information sheet for  
family members/carers**



You are being invited to take part in a research study as your relative, or the person you care for, is (or has been) involved in a collaborative project entitled 'Pressure Ulcers to Zero'. This information sheet explains why the research is being done and what it would involve for you. This will help you decide if you want to volunteer to take part. Please take the time to read this information carefully and speak to others about the study if this would help.

### **The Research Study:**

The title of the study is: ***'An exploration of the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.'***

The study is being conducted for a Masters by Research award and is being supervised by Professor Zena Moore of the Royal College of Surgeons in Ireland and by Dr Sarah Condell, former Nursing and Midwifery Research and Development Lead, ONMSD, HSE.

### **What is the purpose of this study?**

Pressure ulcers, more commonly known as pressure sores or bedsores, are areas of skin damage, usually over a bony area (e.g. elbows, buttocks, heels), which happens when pressure is applied to that area for a long period of time. The purpose of this study is to explore:

1. how patients, being cared for with a 'bundle of care' to avoid a pressure sore developing, find that experience,
2. the relative / carers' (of the patient ) experience, of the care that your relative / person you care for, is receiving (has received) relating to pressure ulcer prevention.

### **What is the bundle of care?**

The 'bundle of care' or the set of preventative measures that are used are known as:

#### **SSKIN**

**Skin inspection:** early inspection means early detection! It is important that a skin inspection be carried out regularly on your relative / person you care for. Any areas of redness, tenderness, soreness, areas of broken skin including blisters, especially over bony areas should be monitored closely.

**Surface:** To assist in reducing any pressure especially over bony areas, specialist equipment such as a mattress or cushion, may be required for your relative / person you care for. Keeping clothing or bedding free from creases and removing any tubing, call bells or mobile phones from under your relatives' / person you care for body can reduce the risk of a pressure sore developing.

**Keep Moving:** One of the primary causes of pressure ulcers is prolonged, unrelieved pressure from lying or sitting on a particular part of the body. If feasible, actively moving and changing your relatives' / person you care for position frequently, can significantly assist in reducing the risk of a pressure sore from occurring.

**Increased moisture to the skin or Incontinence:** Make sure your relatives' / person you care for, skin is clean and dry. By ensuring that his / her skin and clothing is not damp from excess moisture such as sweat or urine, can reduce the risk of a pressure sore from occurring.

**Nutrition & hydration:** If feasible and if allowed by the medical team, eating a healthy balanced diet and drinking plenty of fluids is recommended for your relative / person you care for. Offering your relative / person you care for, regular drinks can assist in keeping skin hydrated.

**Why have I been chosen?**

You have been asked to take part because your relative / person you care for is being nursed (or has been cared for) within the \*\*\*\*\* Primary Care Area, by a team who want to learn from their practice and improve the care they deliver. This team has been part of a quality improvement collaborative project entitled 'Pressure Ulcers to Zero' within the HSE in the Dublin North East area, which aims to reduce the number of pressure ulcers from occurring, by using the 5 elements of SSKIN care bundle, as listed above.

**Do I have to take part?**

Taking part in this study is entirely your decision. If you choose not to take part this will be respected and will not affect your relatives' / person you care for, care in any way. If you do decide to take part you will be asked to sign a consent form before being involved in any activities.

**What will happen during the study?**

If you decide to take part you will be invited to speak with the nurse researcher involved in the study as part of a focus group with other participants, about your experience of the care that your relative / person you care for, is receiving (has received) relating to pressure ulcer prevention.

You will have the opportunity to talk about

- Your experiences of the SSKIN care bundle,
- What you, as a relative / carer, found easy or difficult with the 5 elements of SSKIN,
- What is important to you as a relative / carer
- What would you do to improve you or your relatives' / person you care for experience of the SSKIN care bundle.

With your agreement, the focus group session will be digitally voice recorded to ensure that your experiences are accurately captured. The focus group will take place over a period of approximately 1 hour. The location of the study will depend on facilities available and suitability of the primary care centre. When the focus group commences, if at any stage you want to stop the session for any reason, you may do so.

**Will my information be kept confidential?**

If you agree to take part in this study, every effort will be made to maintain confidentiality of your personal details and that of your relative / person you care for. So, for example, your name and any personal information revealed during the interview will be given a number or other term so that you, or your relative / person you care for, cannot be identified in any way and no personal information will be traced back to you. The digitally voice recorded focus group will be transcribed directly after the interview. Your name or that of your relative / person you care for will not be included in the transcript. The transcript of the focus group will be stored in a secure password operated software system on the nurse researchers laptop, of which she is the only person with access. The only people who may see the transcripts will be the researcher and her supervisor(s) in the Royal College of Surgeons in Ireland. We can make arrangements for you to see the transcript, should you wish to do so. Any future publication of the research findings will not identify you, your relative / person you care for, the healthcare organisation in any way.

**What happens to the information after the study?**

The interview transcripts, with the information you have provided, will be retained for a period of up to 5 years. This information will be stored on a secure password operated server located in the Royal College of Surgeons in Ireland (RCSI) building in Dublin. This is to allow access to information should further research in the area be indicated. There is no intention to re-use the information once the final analysis of the study has occurred.

However, should the need arise to re-visit the research information, approval will be sought from the Research Ethics Committee, prior to any further research being conducted.

Following the 5 year time frame, all of the information will be destroyed when no longer of use to the study. All information will be handled and stored in accordance with the requirements of the Data Protection Act 2003.

### **Confidentiality within the group.**

Please be advised that during the course of the focus group session, some personal detailed information may be shared among the group. Please ensure that any such information be treated with respect. All details disclosed among the group must at all times remain confidential.

### **The possible benefits of the study:**

The information obtained from this study will assist nurses and carers to gain a greater understanding of the importance of the prevention of pressure ulcers using the 5 elements of the SSKIN care bundle, and in particular the patients and family / carers role in that bundle of care. This in turn will allow for a greater quality of care for future patients. It is hoped that the findings of this study will assist when the SSKIN care bundle is used in other wards, units, hospitals or primary care areas outside of the Dublin North East Region.

You may also find that participation in this study is of benefit to you, as it will give you the opportunity to talk about issues you have regarding this subject.

### **The possible risks of this study:**

In the unlikely event that during the focus group session, you find that issues raised or incidents recalled upset you, the focus group will be stopped. The researcher will liaise with the Public Health Nurse in relation to appropriate supports for you, your relative / person you care for. In some instances the Medical team / GP may need to be consulted. In the interest of patient / client safety, if you report an area of poor or dangerous practice, I will need to speak with the relevant senior nurse manager from the area so that action can be taken to prevent similar situations from occurring in the future. Also, if I detect from any discussions with you, that you are at risk of harming yourself or others, I have a duty of care to discuss my concerns with the relevant professional staff in order to ensure that appropriate care or support is provided.

### **May I refuse to take part or withdraw from the study?**

Yes, you may refuse to take part in the study or withdraw from the study at any time, without giving a reason. Should you do so, this decision will be respected and will not affect you or your relatives' / person you care for's, care in any way.

### **What will happen to the results of the research study?**

The results of this study will help to improve practice and the quality of care relating to the patients involvement in pressure ulcer prevention and in particular to the SSKIN bundle of care. The findings will be presented in a dissertation and will be sent for publication in a professional journal and / or presented at conferences.

### **Permission:**

I have been granted ethical approval from the\*\*\*\*\*Research Ethics Committee, the Royal College of Surgeons Research Ethics Committee and the Primary Care Research Committee Dublin North East, to proceed with this study. I have also obtained permission from the relevant people such as the Director of Nursing and the Public Health Nurses to conduct this study within \*\*\*\*\* Primary Care Area.

### **Further Information and Contact Details:**

If you have any queries or would like further information on the study, please ask the nurse to contact me. I will arrange to speak to you at a time that suits you. My contact details are as follows:

**Researcher:**



---

Emma Fleming  
MSc by Research Student, RCSI  
PG Dip Wound Care & Tissue Viability  
Dip First Line Management, RGN.

NMPDU HSE Dublin North  
Swords Business Campus  
Balheary Road  
Swords  
Co. Dublin  
Telephone: \*\*\*\*\*  
Email: [emmafleming@rcsi.ie](mailto:emmafleming@rcsi.ie)



**Thank you for taking the time to read this information.**



# **Appendix11**

## **Consent form for patients**



Name of the study: *To explore the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.*

Please circle **Yes or No** as appropriate:

1. Have you read or had read to you the study information leaflet? **Yes / No**
2. Have you had time to consider the information? **Yes / No**
3. Have you had an opportunity to ask questions and had these answered satisfactorily? **Yes / No**
4. Do you understand the information provided? **Yes / No**
5. Have you received enough information about the study? **Yes / No**
6. Do you understand that your participation within this study is voluntary and that you are free to withdraw from the study
  - At any time ? **Yes / No**
  - Without having to give a reason for withdrawing? **Yes / No**
  - And without affecting your clinical care? **Yes / No**
7. Do you understand that you may be withdrawn from the study, if the study Investigator considers this is necessary and is within your best interests? **Yes / No**
8. Do you understand that all of the information provided during the interview on the digital voice recordings will be transcribed word for word, but that any personal data will be withdrawn / altered so that information cannot be linked back to you as a person? **Yes / No**
9. Do you understand that if you wish to review the transcripts of the digital voice recordings of your interview, you may do so and the researcher will provide them for you? **Yes/ No**
10. Do you understand that the researcher will hold all information and data collected in a confidential manner? **Yes / No**
11. Do you understand that information given during the interview may be scrutinised during audit by the researcher and maybe by properly authorised people (i.e. supervisors)? **Yes / No**
12. Do you understand that after the end of the study, the information and data collected, will be stored on a secure password operated server in the Royal College of Surgeons in Ireland, and that this information will be retained there for a period of up to 5 years? Do you understand that following this time it will be destroyed? **Yes /No**
13. Do you understand that after the end of the study, should the need arise to



re-visit the research information provided by you, approval will be sought from the Research Ethics Committee, prior to any further research being conducted.

**Yes/ No**

14. Do you understand that if poor or dangerous practice is reported, that this will be discussed with the relevant senior manager by the researcher?

**Yes / No**

15. Do you understand that information generated by the study may be published, but that no- one will be able to identify you through the information presented?

**Yes / No**

16. Do you agree to take part in the study?

**Yes / No**

**Participants Name (Block letters):** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Researchers Name (Block letters):** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Researcher Contact Details:**

Emma Fleming.

MSc by Research Student RCSI  
RGN, PG Dip Wound Care & Tissue Viability,  
Dip First Line Management.

NMPDU HSE Dublin North  
Swords Business Campus  
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Swords  
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Email: emmaflaming@rcsi.ie



**Appendix 12**

**Checklist for Researcher**

**Patient Participants**

## CHECKLIST for the Researcher Patient Participants



**Research Title:** To explore the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.

**Site:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Current or Recent Past Participant of the Collaborative:** \_\_\_\_\_

- |    |  |          |
|----|--|----------|
| 1. | <u>1.1</u> Has the participant received the information sheet about the study?   | Yes/ No  |
|    | <u>1.2</u> Have you allowed the participant  |          |
|    | • sufficient time for contemplation of participation in this study, (i.e. 24-48 hours)   |          |
|    | • to consider the matter on his/her own,   |          |
|    | • to discuss with others if wished,  |          |
|    | • ask you questions?   | Yes / No |
|    | <u>1.3</u> Have you given the participant an verbal explanation of the proposed research project?  | Yes / No |
| 2. | Did your verbal explanation to the participant include:  |          |
|    | <u>2.1</u> That this is a research project?  | Yes / No |
|    | <u>2.2</u> The nature of the collaborative?  | Yes / No |
|    | <u>2.3</u> The aims of the project?  | Yes / No |
|    | <u>2.4</u> What is the participant's involvement in the study?   | Yes / No |
|    | <u>2.5</u> The expected benefits to the participant and to others?   | Yes / No |
|    | <u>2.6</u> The procedure, which will be involved in participation? (i.e. interview)  | Yes / No |
|    | <u>2.7</u> What risks, inconvenience, discomfort or distress may reasonably be anticipated for this participant, the level and the likelihood? | Yes / No |
|    | <u>2.8</u> That participation in this study is voluntary?  | Yes / No |
|    | <u>2.9</u> That a refusal to participate may be given without reasons and will not affect their care   | Yes / No |

2.10 That the participant may withdraw from the study at any time without having to give a reason, and that their care will not be affected in any way? **Yes / No**

2.11 That the participant may be withdrawn from the study, if the study researcher or considers this is necessary and is in the best interests of the participant? **Yes / No**

2.12 That information given during the interview may be scrutinised during audit by the researcher and maybe by properly authorised people (i.e. supervisors), but that all information will be treated as confidential and will not be made publicly available? **Yes / No**

2.13 That information generated by the study may be published but that no details will be divulged from which the participant could be identified? **Yes / No**

2.14 That some such information will be retained for a period after the end of the study? **Yes / No**

2.15 Whom to contact if any queries or concerns and how? **Yes / No**

2.16 That if poor or dangerous practice is reported, the researcher will discuss with the relevant senior manager by the researcher? **Yes/ No**

3. Is or has the participant been involved in any other research studies related to this present one? **Yes / No**

4. In your opinion, has the participant understood and consented to take part in this research? **Yes/No**

**Name of the Researcher (Block Capitals):**

\_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## **Appendix13**

### **Family member/ Carer consent form**



**Name of the Study:** To explore the patient and family or carer experience of implementing the pressure ulcer prevention bundle of care (known as SSKIN) within a regional quality improvement collaborative.

Please circle **Yes or No** as appropriate:

1. I confirm that I have read and understood the information leaflet provided to me for the above research study. **Yes/ No**
2. I confirm that I have had time to consider the information. **Yes / No**
3. I confirm that I have had the opportunity to ask questions and that my questions have been answered satisfactorily. **Yes / No**
4. I understand that my participation is voluntary (my choice) and that I am free to withdraw from the study
  - a. at any time,
  - b. without giving reasons,
  - c. and without my relatives'/ person I care for, clinical care being affected**Yes / No**
5. I understand my participation in the study will be as part of a focus group. **Yes / No**
6. I understand that all of the information shared in the focus group session must remain confidential. **Yes/ No**
7. I understand that if poor or dangerous practice is reported, that this will be discussed with the relevant senior manager by the researcher. **Yes/No**
8. I understand that all of the information provided during the focus group session on the digital voice recordings will be transcribed word for word, but that any personal data will be withdrawn / altered so that information cannot be linked back to me. **Yes / No**
9. I understand that if I wish to review the transcripts of the digital voice recordings of my participation in the focus group, I may do so and the researcher will provide me with them. **Yes/ No**
10. I understand that the researcher will hold all information and data collected in a confidential manner. **Yes / No**
11. I understand that information given during the focus group may be scrutinised during audit by the researcher and maybe by properly authorised people (i.e.supervisors) **Yes / No**
12. I understand that after the end of the study, the information and data collected will be stored on a secure password operated server in the Royal College of Surgeons in Ireland, Dublin, and that this information will be retained there for a period of up to 5 years. I also understand that following this time, it will be destroyed. **Yes /No**

13. Do you understand that after the end of the study, should the need arise to re-visit the research information provided by you, approval will be sought from the Research Ethics Committee, prior to any further research being conducted. **Yes/ No**

14. I understand that the information generated by the study may be published, but that no- one will be able to identify me or my relative / person I care for, through the information presented. **Yes / No**

15. I agree to taking part in this study. **Yes/No**

**Name of participant (block capitals):** \_\_\_\_\_

**Signature** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Name of researcher (block capitals) :** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Researcher Contact Details:**

Emma Fleming.

MSc by Research Student RCSI.

PG Dip Wound Care & Tissue Viability,

Dip First Line Management, RGN.

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**Appendix 14**

**Checklist for Researcher  
Family/Carer Participants**





**Research Title:** To explore the patient and family or carer experience of implementing the pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative.

**Participant's Number:** \_\_\_\_\_

**Current or Recent Past Participant of the Collaborative:** \_\_\_\_\_

1.
  - 1.1 Has the participant received the information sheet about the study? **Yes/ No**
  - 1.2 Have you allowed the participant
    - sufficient time for contemplation of participation in this study, (i.e. 24-48 hours)
    - to consider the matter on his/her own,
    - to discuss with others if wished,
    - ask you questions? **Yes / No**
  - 1.3 Have you given the participant an verbal explanation of the proposed research project? **Yes / No**
2. Did your verbal explanation to the participant include:
  - 2.1 That this is a research project? **Yes / No**
  - 2.2 The nature of the collaborative? **Yes / No**
  - 2.3 The aims of the project? **Yes / No**
  - 2.4 What is the participant's involvement in the study (relative / carer?) **Yes / No**
  - 2.5 The expected benefits to the participant and their relative / person they care for and to others? **Yes / No**
  - 2.6 The procedure, which will be involved in participation? (i.e. focus group) **Yes / No**
  - 2.7 What risks, inconvenience, discomfort or distress may reasonably be anticipated for this participant, the level and the likelihood? **Yes / No**
  - 2.8 That participation in this study is voluntary? **Yes / No**
  - 2.9 That a refusal to participate may be given without reasons and will not affect the care of their relative / person they care for **Yes / No**
  - 2.10 That the participant may withdraw from the study at any time without having to give a reason, and that the participants

relative / person they care for, care will not be affected in any way?

**Yes / No**

2.11 That the participant may be withdrawn from the study, if the study investigator considers this is necessary and is in the best interests of the participant?

**Yes / No**

2.12 That information given during the interview may be scrutinised during audit by the researcher and maybe by properly authorised people (i.e. supervisors), but that all information will be treated as confidential and will not be made publicly available?

**Yes / No**

2.13 That information generated by the study may be published but that no details will be divulged from which the participant or their relative / person they care for could be identified?

**Yes / No**

2.14 That some such information will be retained for a period after the end of the study?

**Yes / No**

2.15 Whom to contact if any queries or concerns and how?

**Yes / No**

2.16 That if poor or dangerous practice is reported, the researcher will discuss with the relevant senior manager by the researcher? **Yes/ No**

3. Is or has the participant been involved in any other research studies related to this present one?

**Yes / No**

4. In your opinion, has the participant understood and consented to take part in this research?

**Yes/No**

**Name of the Researcher (Block Capitals):**

\_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Appendix 15**

**Permission to adapt interview &  
focus group schedule  
& associated schedules**

From: e.fleming@live.ie  
To: urmila.victor@hse.ie  
Subject: RE: Interview schedule  
Date: Mon, 29 Sep 2014 12:21:15 +0000

Many thanks Urmila.

Kind regards,  
Emma

Date: Mon, 29 Sep 2014 10:10:55 +0100  
From: urmila.victor@hse.ie  
Subject: RE: Interview schedule  
To: e.fleming@live.ie

Hi Emma,  
Please find attached questionnaires as requested and all the best to you.  
Regards,  
Urmila.

**From:** emma fleming [mailto:e.fleming@live.ie]  
**Sent:** 29 September 2014 06:38  
**To:** urmila.victor@hse.ie  
**Subject:** Interview schedule

Hi Urmila,

I am presently undertaking an MSc by Research at the Royal College of Surgeons in Ireland by conducting a research study. The aim of the proposed research is to explore the patient and family or carer experience of implementing a pressure ulcer prevention care bundle (known as SSKIN) within a regional quality improvement collaborative. My supervisors for this work are Professor Zena Moore, RCSI and Dr Sarah Condell, HSE. I am currently seeking permission from the \*\*\*\*\* Research Ethics Committee to proceed with this study.

Following on from our previous telephone conversation, I would just like to confirm that you are happy for me to adapt your existing interview and focus group schedule that you used to explore patient's experiences of tilting to prevent pressure ulcers, and expand it to incorporate all practices within the SSKIN care bundle.

I would be obliged if you could forward onto me a copy of your interview and focus group schedule at your earliest possible convenience.

If you have any questions please do not hesitate to contact me.

Kind regards,

Emma Fleming.  
RGN, MSc by Research student RCSI.  
Telephone: 086 1679839  
email; e.fleming@live.ie

### **Focus Group Questions**

- 1. When you think about pressure ulcer prevention what comes to mind?**
- 2. Describe what kind of patients you have used the 30 degree tilt technique with?**
- 3. Tell me your experiences of using the 30 degree tilt technique?**
- 4. What are the main advantages of using the 30 degree tilt technique?**
- 5. What are the challenges of using the 30 degree tilt technique?**
- 6. Do you have any comments, questions or suggestions regarding this topic?**

### **One to one interview questions**

- 1. Do you think repositioning is important? Why?**
- 2. Was the information given about the repositioning useful and clear?**
- 3. How did you find the repositioning technique?**
- 4. Did you have any problems with the repositioning technique?**
- 5. Do you find any difference after the repositioning technique over the pressure prone areas?**
- 6. Do you have any comments, queries or suggestions in regards to this topic?**

## **Appendix 16**

### **One to One Interview Schedule**



**Appendix: ONE TO ONE INTERVIEW SCHEDULE (for patients)**

**Location:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Log Number:** \_\_\_\_\_

*As nurses we are very concerned with what we call pressure area care.*

- **Have you ever heard of this and what do you understand it means? Why do you think pressure area care might be important?**

*To nurses pressure area care is about preventing pressure ulcers.*

- **When you hear pressure ulcer prevention, what comes to mind?**

*You have received a bundle of care to prevent pressure ulcers, which we call SSKIN. (an explanation of SSKIN will be provided, if necessary)*

- **Were you told about SSKIN? How? When? By whom? (prompt re patient information leaflet)**
- **As a patient, what do you see as your role in SSKIN? Why?**
- **How did you find the SSKIN care bundle overall?**
- **Did you have any problems with the SSKIN care bundle?**
- **How involved did you feel in the individual elements of the SSKIN bundle? What elements of the bundle did you find easy/most useful and why? Did you have difficulty with any elements and why?**
- **Do you find any difference in your pressure area care since you have been introduced to the SSKIN care bundle?**
- **Do you have any suggestions or comments that would improve your role in the SSKIN care bundle?**
- **Was information given to you about the pressure ulcer prevention collaborative *pressure ulcers to zero*? If yes, what did you find useful/not useful and why?**
- **Is there anything else to wish to tell me about your experiences of the SSKIN care bundle?**

*Probes will be used for each question as required. For example, Can you tell me a bit more about...? What do you mean when you say...? Etc.*

## **Appendix 17**

### **Focus Group Schedule**





As nurses, we are very concerned with what we call pressure area care.

- **Have you ever heard of this and what do you understand it means? Why do you think pressure area care might be important for your relative / person you care for?**

To nurses pressure area care is about preventing pressure ulcers

- **When you hear about pressure ulcer prevention for your relative / person you care**

Your relative / person you care for has received a bundle of care to prevent pressure ulcers, which we call SSKIN. (an explanation of SSKIN will be provided, if necessary)

- **Were you told about SSKIN? How? When? By whom? (prompt re relative / carer information leaflet)**
- **As a relative / carer, what do you see as your role in the SSKIN care bundle? Why?**
- **As a relative / carer, overall how did you find the SSKIN care bundle in caring for your relative / person you care for?**
- **Did you or your relative (the patient / person cared for), experience any problems with the SSKIN care bundle?**
- **As a relative how involved did you feel in the individual elements of the SSKIN bundle? (this relates to acute / residential setting)**
- **What elements of the bundle did you find easy/most useful and why? Did you have difficulty with any elements and why?**
- **Do you find any difference in your relatives' / person you care for, pressure area care since you have been introduced to the SSKIN care bundle?**
- **Do you have any suggestions or comments that would improve your role in the SSKIN care bundle?**
- **Was information given to you about the pressure ulcer prevention collaborative 'Pressure Ulcers to Zero?' If yes, what did you find useful/not useful and why?**
- **Is there anything else to wish to tell me about your experiences of the SSKIN care bundle?**

Probes will be used for each question as required. For example, Can you tell me a bit more about...? What do you mean when you say...? Etc.

## **Appendix 18**

### **A Sample Interview Transcript**

**Data Collection Interview: Patient N**  
**Date: Tuesday \*\*\*\*\* 2015 @ 09.30**  
**Location: Acute site. In the family room.**  
**Duration: 36.59 minutes.**

**1.So, ##### you have signed your consent form?**

2.I have.

**3.And you are happy enough to go ahead?**

4.Very happy.

**5.And you understand why we are here today and what the study is about?**

6.Absolutely, yes. I do indeed yeah.

**7.So, I suppose we will start off then (pause). As nurses, such as myself, we  
8.are very concerned about what we call pressure area care. Have you ever  
9.heard of this?**

10.I have. Oh I have, I have. I had elderly grandparents and you would always  
11.hear about bedsores. Em, you would hear it with any elderly people in hospital  
12.you hear oh the bedsores are bad. Em, in my own personal experience, eh,  
13.when I was in my late teens, early 20's, em I worked in a hospital as a porter  
14.and I remember helping nurses turn patients eh, in bed eh, hold them while  
15.they cleaned their backs and that. And I remember one particular patient from  
16.##### and he had a really bad bedsore. So I witnessed firsthand when I was  
17.about 19 or 20. So yeah I have heard of it, yeah.

**18.When you say elderly people, do you only consider that PUs only occur in  
19.elderly people?**

20.No. Not necessarily. I know eh, say from, from experience like that if  
21.somebody's .overweight and that they are in, they are after an operation in  
22.hospital or wherever and they wouldn't or they mightn't have the energy or the  
23.strength to move or turn themselves. Eh, but it isn't necessarily related to age,  
24.no.

**25.And when you say that you have seen it firsthand, do you think this is an  
26.important aspect for you being a patient now, that you have a better  
27.understanding of it?**

28.Oh there is no doubt that it does give one a better understanding, having  
29.witnessed it and eh, clearly not experienced on a personal level but seeing  
30.somebody else suffering it does make a difference yeah. Definitely. It does  
31.make a difference.

**32.If we talk about pressure area care, what do you understand that it  
33.means?**

34. Well for me like it means that first of all eh, that somebody (coughs), somebody  
35. identifies the risk. When having identified the risk then that there are certain  
36. steps to follow to help the carer and the person being cared for cope with it.  
37. And, em for example when I got this little leaflet here from the nurses last week,  
38. and like they explained to me that the danger of if I don't keep or didn't keep  
39. moving in the bed, if I wasn't getting sitting up by the side of the bed that the  
40. risk was that I would suffer from pressure sores and then having made me  
41. aware of that and when I read the leaflet I know straight away. Eh, and I  
42. probably should have known already eh, the importance of moving in the bed  
43. or if you are not getting up. It's key to the avoidance of things going wrong.

**44. So did you find that information leaflet useful?**

45. I actually did yeah, I actually did. And I noticed myself em, I'm not sure if was  
46. consciously or subconsciously just moving you know and changing my legs or  
47. switching positions in the bed and eh, I said yeah, yeah, yeah, that makes  
48. sense. That makes sense. So yeah I thought that, well I think that's a good  
49. leaflet.

**50. Other than the leaflet, did you receive any other forms of information  
51. about PU prevention?**

52. I actually didn't and one of the things that occurred to me when I read and  
53. when I met you on Friday and then when I read the detail sheet, I started  
54. thinking about it. Em, the thought occurred to me that it mightn't be any harm to  
55. have that SSKIN poster behind your head there, em that if you had other  
56. prompts on a sheet like that laminated over the bed. Now, obviously it won't  
57. affect every patient, but it's just a suggestion that I would have, eh, for the  
58. carers (HCPs) to prompt them to look even whether its subconsciously they  
59. notice. You know sometimes like when you see the signs at the sinks about  
60. washing your hands and so like once you are trained and trained properly then  
61. you will follow the steps. But the reminder is there in the background or in the  
62. corner of your eye that you 'Oh God look this patient here, he or she might be  
63. lying on the alarm bell or might be lying on a drain or whatever. So to have a  
64. checklist on the wall so they say he's for an operation or she's for an operation  
65. yeah, we better check that all the drains are free, check that the call bell is free  
66. and that in his or her hand and that they are actually not lying on the drain or a  
67. cable as a case may be.

**68. And do you think that a prompt card like that may be useful for as a  
69. patient as well?**

70. Oh I think it would, I think it would. Now I think a lot of the time eh, and I hope  
71. this doesn't come out wrong, eh, that it might be too late in a sense that like  
72. that em, when you are conscious as if you are totally out of it, you won't see a  
73. prompt. But equally when you start coming around and you are seeing the  
74. prompt you say 'God yeah, yeah oh what way am I lying? what am I lying on?'  
75. and you call the nurse and you say my drain is under my body here I think  
76. would you mind checking or whatever. So it could be a help.

**77.**So you spoke there a little bit about drains and call bells some of the  
**78.**medical equipment. If you don't mind me asking how long have you been  
**79.**here now in the hospital?

80.I came in here on Wednesday the \*\*\*\*\* and I was operated on the \*\*\*\*\*.

**81.**So would you have had a lot of attachments connected to you such as  
**82.**drains and so forth?

83.I would have had. I had 4, 4 drains eh, I had a catheter, I had a tube out of my  
84.nose . Eh, I had obviously the wound itself em, and that's about it I'd say but I  
85.have had all those in between from \*\*\*\*\**(Unit Name)* to \*\*\*\*\**(Unit name)* to the  
86.ward. But as you move through eh, from different areas , the number of tubes  
87.reduce. So like the last tube was removed on, the last drain was removed on  
88.the Friday so that would be the 9<sup>th</sup> day. Last Thursday would have been the 8<sup>th</sup>  
89.day, and the Friday morning then, the last drain was removed. But I was more  
90.mobile them, I was able to get around and I wasn't eh, I had seen the leaflet  
91.and having spoken to so my risk even if I say so myself I believe my risk was  
92.low. But that was down to me. Somebody else getting the same operation as  
93.me, em, mightn't have been.

*(pause)*

**94.**To nurses, we consider pressure area care about preventing pressure  
**95.**ulcers.

96.Yeah.

**97.**So when you hear PU prevention, what comes to your mind?

98.What comes to mind is that there is eh, communication. For me I think  
99.communication is the most important thing and I think when amongst the  
100.nursing group, for want of a better way of describing it, is eh satisfied that the  
101.patient can comprehend eh, that the communication should start then and that  
102.the explanation of pressure sores and eh, and ulcers and all that type of thing  
103.is explained to the patient at that stage. And that the patient em, I mean part  
104.of, it's part of the patients' responsibility to well, to take responsibility for parts  
105.of their own care as well, particularly when pressure sores are at risk and like  
106.it's all very well to say you know you shouldn't be shouldn't be doing that eh,  
107.but the patient must co-operate.

**108.**You am I correct in saying that you think communication is important for  
**109.**you?

110.Yeah communication is key, yeah. That's key.

**111.**So does anything else come to mind when you hear the word prevention  
**112.**or preventing pressure ulcers?

*(pause)*

113.I don't think so. The basic thing is explaining to somebody, yeah look we don't  
114.want you to get bedsores and the reason you get bedsores is or also the  
115.pressure points is because of this, that, or the other can happen. The impact  
116.of pressure sores are that you can serious infection like the story I was telling  
117.you about earlier, like that poor man, like he had a hole in his back the size of  
118.my fist. I was 19 at that time or 20 maybe and I have never forgotten it. So, I  
119.mean it's just to explain to them for patients, this can go really, really wrong  
120.eh, and so, and just say to them look we need your co-operation here and eh,  
121.we need you to be a bit more maybe eh, proactive about getting out of the  
122.bed, sitting out, going for walks or if you can't do that, if you are too weak, em  
123.ask the nurses to move you. Because nurses are busy, really busy people and  
124.anybody who spends time in hospital can see that and but I have to say, my  
125.experience of being her in ##### has been nothing but positive, because they  
126.are all very proactive. But it can happen that they would be so busy, a nurse  
127.can be so busy eh that they might eh mightn't have time to stop and think 'oh  
128.God #### is in bed, oh he hasn't 1moved in the last 2 hours. We better move  
129.him so.' Like it would be up to me to say nurse would you mind turning me  
130.here eh, because I haven't moved, I'm conscious of the danger of getting  
131.pressure sores and I just need you turn me left, right or sit me up. Or you  
132.know there might be, say the physio might come and say pull the clothes off  
133.and say you know lift your legs. You know bend your knees, that type of thing.  
134.So I'd say it would be, it's a 2-way street. Definitely a 2-way street between  
135.staff and the patient.

**136.While you have been here on ##### you have been receiving a bundle  
137.of care to prevent pressure ulcers form occurring and that's what we call  
138.SSKIN. S.S.K.I.N., an acronym or a play on words that we use to  
139.describe the care bundle. So the first S stands for Skin inspection, the  
140.second S stands for the Surface, the K is for Keep moving, the I is for  
141.Incontinence or moisture on the skin and then the N is for Nutrition and  
142.hydration. So were you ever told about SSKIN , about the S.S.K.I.N?**

143.I was. Eh, what I would have to say here is it was later. For the objective of  
144.your study I would have felt that I might have been told about it a little bit  
145.earlier. Eh, but having said that, when you come out of an operation and you  
146.are in ### being the first step, you are in no condition to absorb information. A  
147.day or so later when you are in the ###, you are a bit more capable of being  
148.eh, assessing stuff. And I have to say, my experience of that again you are  
149.still not independently mobile. A lot of the work if not all of the work is done by  
150.the nurses because they are turning you and they are changing you. They are  
151.checking you, so in the sense that the principles of SSKIN were applied but I  
152.wasn't conscious that it was SSKIN was being done. But as I came through  
153.the later stages of the process, clearly I understood then. So I think em, it was  
154.probably the approach was probably the most practical way of approaching it  
155.because as I said already you are not really em, first of all capable of  
156.absorbing the information not alone implementing it.

**157.Am I correct in saying although you may not have heard about the  
158.SSKIN initially, would you have felt that all of the actions involved  
159.within the SSKIN would have been implemented?**

160.I would have thought the communication part happened later but the  
161.implementation part happened at the right time. It was going on, I wasn't  
162.saying to myself oh this is SSKIN or I wasn't saying to myself oh they are  
163.preventing bedsores em, but I was saying to myself yeah they are looking  
164.after me.

**165.Can you remember who told you about the SSKIN care bundle?**

166.No. It was one of the nurses came to, no sorry 2 of them came together, and  
167.they said like you know, we are going to give you this leaflet here, eh the  
168.SSKIN leaflet. The reason for it is that eh you need to be a bit more active,  
169.you need to move in the bed if you are not getting out and eh, I listened to  
170.what they had to say to me. Eh and it was grand.

**171.As a patient here, what would you see as your role within the SSKIN?  
172.Within the 5 elements of the S.S.K.I.N?**

173.I would say co-operation. Eh, is the name.

**174.Co-operation? in what sense?**

175.Co-operation in a sense that you follow the advice that you are given. Eh,  
176.because certainly the advice that was communicated to me at the later stages  
177.was done very well. It was very effective and eh, it made me aware, eh that  
178.there was stuff I should be doing as part of my own care to make sure that  
179.these things didn't go wrong.

**180.And what type of things would that involve?**

181.Well it would have been like you know as I said, eh, moving. Lifting my legs.  
182.Moving and changing position in the bed. Get up and go for a walk. Now  
183.having said that I was at the stage where I probably wasn't as mobile as I am  
184.now. Well I wasn't. You know.

**185.Well definitely even since I met you on Friday, you have come on great.**

**186.(Laughs)** I know I have come on in leaps and bounds in the last few days.

**187.It's great to see.**

188.Thank you yeah, yeah.

**189.So if we break up each of the elements of the SSKIN care bundle, and if  
190.we talk about the first S which is the Skin inspection, what do you  
191.understand that this means?**

192.Well what I would see first of all clearly when you're sick and you're  
193.recovering there are parts of your body that you can't see and then having  
194.said that when you are not sick there are parts of your body that you can't see  
195.like your back, your behind you know. For me it would be the nurses

196.inspecting those areas. Checking you and turning you. Checking your  
197.back and I know certainly that when I was in ### (*Name of unit*) that a  
198.regular occurrence. My back was constantly eh, being eh, lathered with cream  
199.and kept moist and eh so that I knew eh, what was happening. While it wasn't  
200.in my foremost in my mind but now looking back I know that the reason for all  
201.this was to make sure that I didn't get sore.

**202.And when you came back here to the ward, did you notice anything  
203.different?**

204.Not as often because I think I was a bit more mobile.

**205.Was that explained to you?**

206.Yeah.

**207.So if we move onto the second S, the surface. Can you tell me a little bit  
208.about the surface. Did you receive any special equipment or anything  
209.we'll say a mattress?**

210.Em. No. It was a standard mattress, in the ward. In the ### (*named unit*) I  
211.presume it was one of these air mattresses. Eh, and I had the TEDS on my  
212.legs eh, and they were ones that being washed or cleaned or turned or the  
213.bed being made or changed, em the TEDS were always on.

**214.And when you say that the TEDS were always on, what do you mean?**

215.Oh yes. I mean that there was a procedure. The socks were rolled down,  
216.checked. It was checked. The socks were back up again. The heels checked,  
217.The soles of the feet checked. Eh, and eh, TEDS turned back on and then you  
218.get on with recovering.

**219.And when you were sitting out then, can you tell me how you found that  
220.experience?**

221.Em, the chair was OK actually. It hadn't crossed my mind at all. It wasn't bad.

**222.Did you ever sit on a cushion or pillow?**

223.Oh I sat on a pillow.

**224.Did you find that you used many pillows while you were in the bed or  
225.sitting out?**

226.Well I em, (*pause*) For sitting up straight yeah, I would yeah, but for sleeping I  
227.go with the minimum.

**228.And when you say the minimum, what would you have found was your  
229.most comfortable position?**



230. My preferred position, would be on my side. Eh I tend to sleep on my front but  
231. I can't do that at the moment eh and eh I would probably say on my back.

**232. And would you have been lying flat or at an angle?**

233. At an angle. I would have thought, well I would have said, if I was lying at an  
234. angle it would probably be about 60 degrees maybe.

**235. And you found that was your most comfortable?**

236. Yeah. I was grand yeah.

**237. And when you were in the bed did you find that you would reposition  
238. regularly?**

239. Yeah, regularly. Oh regularly.

**240. Why was that?**

241. It was more discomfort, to try to get into a more comfortable position, for a  
242. while anyway.

**243. If you can recall where would the discomfort have been?**

244. Just generally on the front of the tummy there.

**245. Did you feel any other discomfort?**

246. No. Definitely no.

**247. So that follows on into the K for keep moving. So when you were in the  
248. bed you were saying earlier on that you were lifting your legs and  
249. repositioning yourself and that. Was it ever explained to you why you  
250. were told to do this?**

251. Well in the context of the SSKIN leaflet, yes because that probably is what  
252. prompted me to do it in the first place. It made me realise it's important

**253. Did anybody ever say to you about mobilising in relation to PU  
254. prevention?**

255. Not in the beginning but later yes. The nurses are talking about moving, but  
256. it's not so much in the context of pressure ulcers, but I can imagine that is eh,  
257. what they mean.

**258. And when you mobilised can you tell me a little bit about that?**

259. Eh, the very first time I got out, it was tough. I moved em, when I was in ####  
260. and that was on the Monday after my operation and I got this kind of s  
261. stainless steel trolley for want of a better way of describing it and I was still on  
262. oxygen at that stage. The physios put me standing behind it and had me just

263.put my hands on it for support and I'd push that eh, ahead of me eh,  
264.around the centre block of the ###. When I got back to the ward it was he  
265.physio again but eh, I was a bit stronger and I didn't need the walking aid  
266.type of support at all.

**267.Did the physio ever explain to you pressure ulcers?**

268.Oh God yeah. Yeah .Yeah.

**269.In what way?**

270.Ah, just mentioned really.

*(pause)*

**271.So going back to when you were sitting out in the chair, did you find that  
272.you would move yourself in the chair?**

273.Oh I would yeah, yeah. I would just kind of you know switch my legs across  
274.from my legs or whatever, kind of shuffle

**275.So moving onto the next section which is the I, for Incontinence or  
276.moisture. Does anything come to mind from your experiences?**

277.I think this time around I was ok. Eh, the last year when I had my operation,  
278.my personal opinion in hindsight now is that they took the catheter out too  
279.soon. It was in about 3 days or 4 days longer this time an it was within 20  
280.minutes of the catheter being removed eh my bladder was working normally  
281.so I didn't really have a problem

**282. What about perspiration? Is this something that you experienced?**

283.I haven't done much. Maybe once or twice, but not very often.

**284.it's not something that you would have been uncomfortable with?**

285.No. No. No. Particularly now with the stoma that I have. Like I am very  
286.conscious about cleaning. Cleaning around it. That specific area but generally  
287.from a hygienic point of view just washing and keeping your body clean yeah  
288.that's important.

**289.Was it explained to you in relation to pressure area care?**

290.No, not in that context, no. But I would imagine that it would be important to  
291.protect your skin from getting what would you say-excoriated.

**292.Ok so Moving on the N which is for Nutrition and hydration. Can you tell  
293.me a little bit about your experience of that here?**

294. Well I had, I had the TPN. They left that go as long as they possibly could  
295.and eh, that was disconnected eh on Friday which should be the 8<sup>th</sup> or 9<sup>th</sup> day

296.after the operation. But I mean I was grand. That was their decision. I was  
297.weaned on to normal food for want of a better way of describing it, in context  
298.of taking yoghurts and jelly and ice cream eh and that and em, I was talking  
299.to##### (nurse) this morning and she was asking me about my eating and my  
300.appetite and I was saying to her look you know it isn't 2 weeks since the  
301.operation so like I'm not expecting miracles. But I am eating ok.

**302.Do you take any nutritional supplement drinks or anything?**

303.Yeah I have been put on eh, fortijuce and I was on similar ones before I came  
304.up and I find them good. They are good.

**305.So would you see the dietician then?**

306.Oh yes, most days.

**307.Did they ever mention pressure area care with nutrition?**

308.Not that I can think of.

**309.Do you think there is a link there or do you think that it is important?**

310.Well I think it probably is actually yeah I think it probably is.

**311.Why would you think that?**

312.Well I think you know anything that, like no one thing works on its own so well  
313.they are all linked and to help people understand. Like it's all about building  
314.bridges and building blocks. More than building bridges. And like when all  
315.building blocks are in place then you're heading up the gap closer to them.

**316.That's a good description.**

*(laughs)*

317.Yeah.

**318.I suppose now that we have spoken about each of the elements of the  
319.SSKIN care bundle, what do you think out of all of them would have  
320.been most applicable to you as a patient?**

*(pause)*

321.I'd say, eh, the skin inspection. Skin inspection I'd say. Because for the 11  
322.days or so that I am here, for over half of them particularly the first half eh I  
323.wouldn't have been conscious or capable of doing things for myself so, I think  
324.I want to have somebody else to do the key things for you and identify the  
325.risks and the needs and the requirements on your behalf. Then I think having  
326.somebody there to inspect you and do it and identify issues or identify  
327.potential problems when you can't do it yourself is the key. I think after that  
328.again it's back to communication and explanations and helping people

329.understand like I have just done this because, now I know you can't look at  
330.your back all the time, you probably can't look at your back at all (*laughs*). But  
331.it will help us help you if you do X, Y and Z. But I think as I said already, for  
332.me it's a 2 way street and like the nurses can only do so much and if the  
333.patient isn't co-operating isn't probably the exactly the right phrase to use but  
334.if the patient isn't participating the patient is our loser. Because you can't force  
335.somebody to do something.

**336.So how did you find the SSKIN care bundle overall?**

337.I thought it was very good and I think it is very effective.

**338.Do you see any problems with it?**

339.Em, no the only suggestion that I have would be eh, the point I made at the  
340.start of this process. If you had your prompts by the side of the bed and as I  
341.said that can work in 2 ways. The nurse who is being trained em, but more  
342.importantly so the patient can understand it as well. Have it structured in such  
343.a way or laid out in such a way like, a lot of these things can be a visual thing,  
344.it can be a much more effective communication that works. And eh, I think  
345.reading works too. Eh, I think it would help the patient as well. That would be  
346.my main suggestion.

**347.Do you think that there is enough awareness about it?**

348.Well I think that if you need the eh, the prompts or the aid memoir or whatever  
349.you want to call them near or next to the bed eh that will achieve that.

**350.So how involved did you feel in each element of the SSKIN care bundle?**

351.Well in the context of being the sick person, I suppose you clearly you are  
352.directly involved. In the context of awareness and eh, communication eh there  
353.wasn't a huge amount. But I think it didn't affect the standard of care that I got.

**354.What parts of the SSKIN care bundle did you or do you find most useful  
355.of the S.S.K.I.N in pressure ulcer prevention?**

356.I suppose the most suitable for me eh, goes back to the point that I mentioned  
357.earlier when I said about the skin inspection. Eh, because that happens at a  
358.stage where you're at your lowest and most exposed and the risk is the  
359.highest I think. And you have people there that are properly trained and more  
360.importantly applying training, eh and properly, and to a high standard, then the  
361.people who are on the receiving end can only benefit.

**362..Do you see any difference or did you see any difference in your  
363.pressure area care since you were introduced to the SSKIN?**

364.No. No.

(*pause*)

**365.Going back to what you were saying earlier on, that it is a ‘2-way street’  
366.between nurses and the patient, how would you suggest that this  
367.happens?**

368.I would say encouragement and reminders and again I think the aid memoir at  
369.the side of the bed and the nurses had when we will say making the bed or  
370.when they are talking to the patient or whenever, don’t forget to look at the  
371.chart there, to reinforce it. It’s all communication.

**372.So was any information ever given to you about the Pressure Ulcers to  
373.Zero Collaborative?**

374.No

**375.Or did you ever see this symbol here?**

376.I did but only recently to be honest, because of this study.

**377.So we are nearing towards the end there #####. Is there anything else  
378.you would like to tell me about your experiences of the SSKIN care  
379.bundle or pressure ulcer prevention?**

380.No. I suppose all I can say is I have been very lucky in the sense that I didn’t  
381.have any issues with my back or my legs or my heels, and eh, but I would say  
382.it seems to me eh that the care staff here are very much aware of it em it’s not  
383.in the context or the sense that it’s in your face, but it’s happening and you  
384.don’t realise that it’s happening.

**385.So if there was a patient in a similar predicament to yourself and you  
386.could give them a piece of advice pertaining to pressure area care, what  
387.would you say to them?**

388.I would say listen to what you are being told. Eh and eh make every effort to  
289.help yourself.

**390.Ok anything you would like to add?.**

391.Is that it?

**392.Yep! Thanks you very much #####**

393.Oh my God. All over?

**394.Unless there is anything else you would like to tell me?**

395.No. No I’m good. I’m good now (*laughs*). Get me to my ambulance now and  
396.take me home! (*Laughs*)

**Appendix 19**  
**A Sample of Formulated Meanings**  
**and Themes**

**Some examples of how the theme ‘Family Involvement’ was constructed from different clusters of themes and formulated meanings.**

<b>Significant Statements</b>	<b>Formulated Meanings</b>	<b>Cluster Theme</b>	<b>Emergent Theme</b>
<i>“Some of it is training families as well in terms of what can families do while they are sitting at the bed. So I think it’s really, well everyone that has a role with that patient should be informed. Family should be maybe be told what to do, especially if the person is in hospital for more than * or * weeks when it’s going into nearly * months. They should really be told ‘look if you see this or see that, this is the person who you come to and tell’.....”.</i>	Carer wanted to be informed through verbal communication and wanted participate in care	Seeking more involvement	Family/Carer Involvement
<i>“You see I don’t know health and safety but if there was a role that the hospitals allowed families to come in and do something. We would be very clear not to do something until somebody would tell us.”</i>	Carer is unsure of their limitations in providing care.	Seeking more involvement	Family/Carer Involvement
<i>“....the different pillows, I always try and get a nice soft one for ****(spouse). There’s not too much I can do so I think it’s important that you know these little things, they mean a lot”</i>	Carer seeks ways to be more involved no matter how big or small	Seeking more Involvement	Family/Carer Involvement
<i>“Well I don’t really have a role anymore, sure I don’t? I just come into visit. Yeah, no I haven’t got any role. I know they will look after her and please God it won’t happen”.</i>	Carer sees themselves as a visitor & does not consider being involved in the care of their family member.	Primary Carer versus Visitor	Family/Carer Involvement

<p><i>"Well I would imagine that they check *****(spouse) when they turn her and when they are washing her, they would look out for areas on her skin that are tender that you wouldn't see normally because of pyjamas and things like that . Because I wouldn't get to see the areas of her body. Like I used to when I had her at home you know, that they, well I perceive that they do and that's what happens."</i></p>	<p>The carer is unaware of the exact care provided, compared to when the Carer looked after family member at home</p>	<p>Primary Carer versus Visitor</p>	<p>Family/Carer Involvement</p>
<p><i>"The creams would come out. The washing would be done and the creams would come out again! And then it depended on the level of disability of my *****(spouse)at the time. But you took action as best you could"</i></p>	<p>Proactive and fully engaged in the delivery of care.</p>	<p>Primary Carer versus Visitor</p>	<p>Family/Carer Involvement</p>
<p><i>"...I check the heels the elbows, everything. So that is very important. I check also in the morning and evening time and if there is some redness I will rinse it with warm water before I put the cream on..... I will ring the nurse if I'm worried and she checks it with me"</i></p>	<p>Aware of what to monitor for in relation to PU prevention and seeks confirmation from nurse</p>	<p>Primary Carer Versus Visitor</p>	<p>Family/Carer Involvement</p>



**Appendix 20**

**Samples from the Writer's**

**Reflective Journal**

### **Example A: Reflective note on the study**

*“ I met a potential study candidate today. A lovely lady, very chatty, more than me! She was in the pre-operative stages of her hospital stay. Other than her diagnosis she appeared in reasonably good health and fully mobile. I spoke in length with her and she seemed to be very interested in the study. However she declined to take part as she felt that she had nothing to offer the study. While she had limited knowledge on PUs she recognised that mobility had a lot to do with it. It was for this reason that she respectfully declined to take part in the study. She felt that she was not at risk of a PU because she was fully mobile. I wonder though would she still think that next week following her surgery? Does she recognise that she will be immobile? It doesn't appear to be that way. What of any pre-operative education? Actually this may be an interesting concept to look at into in the future the differences between pre and post op knowledge on PUs and patients perceptions. It is an interesting thought. Make note of this+++++”*

### **Example B: Observational field notes**

*\*note the body language\*.*

- When speaking of 'floating'- his arms are up in the air, eyes closed, deep breath. He has remained so when recalling his experience.*
- Pointing to sacral region but refers to it as his 'back'*
- Frustration over pressure relieving cushion- arms in the air questioning stance then hands to his forehead -resembling stress/upset?*
- Demonstrates how he manoeuvred in the chair 'shuffles' from side to side then re-enacts standing up with medical device attachments- pointing to imaginary drip stand and catheter bag.*

*Make note+++++++, similar report to previous interview mane regarding the medical attachments. Restricting mobility+++++*

- Reports 'wishing'- does that indicate pain/ discomfort? Make a note++++++*
- Points to the poster and holds in position when explaining - 'why isn't it told more?'*

### **Example C: Personal reflection:**

*"I rang the administrator again but to no avail. It has now been almost 3 weeks since I re-submitted the recommended changes. The last few days have proven very tedious and frustrating. It's hard not having any control over the situation. The whole process is just going so much slower than I thought, I expected to be in the field by now collecting data. Like I'm all ready to go! And Christmas is approaching! I hope that the time is not going to affect the study, but I have a feeling that it might. I can only be in one place at any time. It's not just the data collection but I have to take into account the preliminary meetings also and the possibility of having to recruit more participants oh and don't forget I may need to recruit through HIPE. I'm just not use to having to rely on others to get things done. But I have to remember IT IS OUTSIDE OF MY CONTROL! I am meeting with \*\*\*\*\*and\*\*\*\*\* (supervisors) later so I will have a chat with them about it and the timeline. I will have to re-draft the Gantt chart so I can keep up with the time schedules. Make a note+++++++ In the meantime I will try and get a few other things done:*

- Access articles for Literature review.*
- Speak with supervisors*
- Speak with Gatekeeper in PCA re opening schedule for Christmas/New Year.*

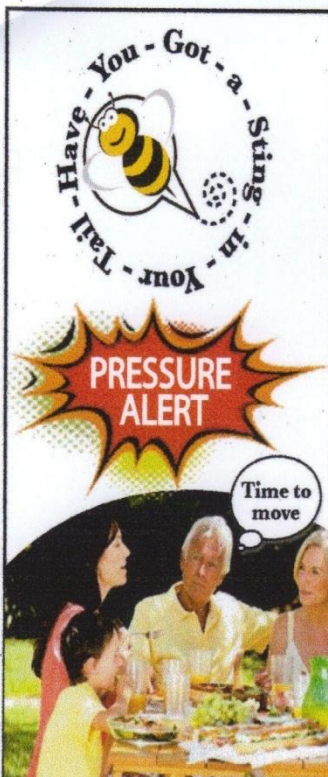
### **Example D: Reflective thoughts following an interview**

*"I have just completed a one to one interview with a very nice lady. I'm quite surprised though by her comments re: not considering herself to be at risk of a PU. Both extrinsic and intrinsic factors apply for PU development. She is significantly dependent on others, restricted mobility, carer to assist with hygiene needs, fragile skin, poor PO intake, requires surface supports etc. yet she is unaware of her risk of developing a PU. She puts it down to the fact that because she has never had one so she is not at risk of one. This is an interesting concept. Make a note+++++++ Where is the communication from HCPs? She is linked with full MDT. She relayed that information has been given to her re pressure area care but by nurses only and to what extent? Why hasn't the risk been made clear to her? Do the staff not recognise that she is at risk? On the flip side, has she been told, but has not absorbed the information relayed to her? Further, did she fully*

*comprehend the message being delivered? I cannot assume anything or generalise. However I will look at previous interview from this site to see if any comparison . Also the next participant may provide further insight re staff communication.”*

## **Appendix 21**

### **‘ PROMPT’ Card**



### **"Prompt" - To Aid the Prevention of Pressure Ulcers in the Community**

**P = Pressure Points**  
Regularly check areas of the body that may be under pressure

**R = Red - Report it**  
Report PROMPTLY to your GP or Nurse any painful areas.

**O = Oral Intake**  
It is important to eat a balanced diet and drink plenty of fluids.

**M = Moisture**  
Keep the skin clean and dry. Use a mild soap and a simple moisturiser.

**P = Position**  
Poor position can contribute to development of pressure ulcers.

**T = Take pressure off**  
Keep moving, changing position at least twice hourly. If unable to please contact a member of your local primary care team.

## **Appendix 22**

# **Pressure Ulcer Classification System**

## International NPUAP/EPUAP Pressure Ulcer Classification System

(adapted from the NPUAP/EPUAP/PPPIA Prevention and Treatment of Pressure Ulcers quick reference guide 2014)

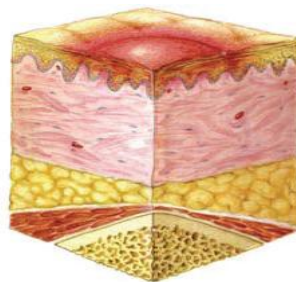
**Definition of a Pressure Ulcer:** *“A pressure ulcer is localized injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear. A number of contributing or confounding factors are also associated with pressure ulcers; the significance of these factors is yet to be elucidated”*

(NPUAP/EPUAP/PPPIA 2014:12)

### Category/Stage I Pressure Ulcer:

#### ***Non-blanchable erythema of intact skin.***

Pain, temperature (warmer or cooler as compared to adjacent tissue), discoloration, induration, hardness or softness of the affected area, may be used as indicators of detection, particularly on darkly pigmented skin. (The rationale for the inclusion of a grade I pressure ulcer damage has been well discussed within the literature. A consensus has emerged that it is an important indicator of risk for the development of more severe pressure ulcer development (Beeckman *et al.* 2007, Moore *et al.* 2011).

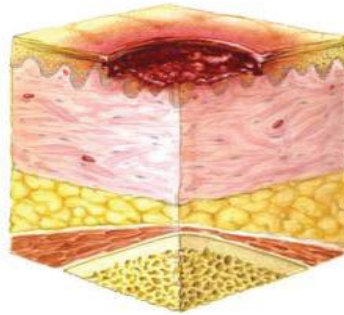




### **Category/Stage II Pressure Ulcer:**

#### ***Partial thickness skin loss.***

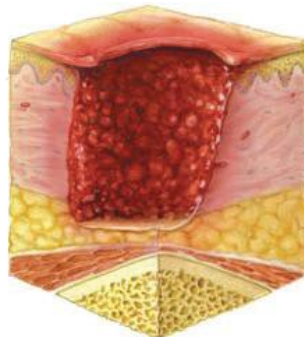
Partial thickness loss of dermis presenting as a shiny or dry shallow open ulcer with a red pink wound bed, without slough or bruising (Bruising indicates suspected deep tissue injury). It may also present as an intact or open/ruptured serum-filled blister. It is advised that this category should not be used to describe skin tears, tape burns, perineal dermatitis, maceration or excoriation.



### **Category/Stage III: Pressure Ulcer:**

#### ***Full thickness skin loss***

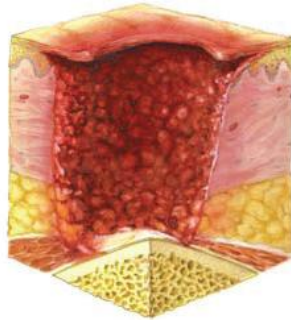
Full thickness skin loss involving damage to the subcutaneous tissue that may extend down to but not through underlying fascia. The bone, tendon or muscle are not exposed. Slough may be present but does not obscure the depth of tissue loss. Undermining and tunneling may be included.



#### **Category/Stage IV Pressure Ulcer:**

##### ***Full thickness tissue loss***

Extensive destruction with full scale tissue loss involving bone, tendon or muscle exposure. Slough or eschar may be present on some parts of the wound bed. Undermining and tunneling are often included.



#### **Unstageable: Depth Unknown**

##### ***Full thickness tissue loss with unknown depth.***

Full thickness tissue loss where the base of the ulcer is covered by slough and /or eschar to the wound bed. The true extent of the wound is unknown until such a time that the slough and/or eschar is removed to expose the base of the wound. Therefore the depth and Category/Stage cannot be identified.



## **Suspected Deep Tissue Injury: Depth Unknown**

### ***Unknown Depth***

A localised area of discoloration of intact skin (purple or maroon) or blood-filled blister as a result of damage of underlying soft tissue injury from pressure and/or shearing forces. Additionally the area may be preceded by tissue that is painful, firm mushy, boggy, warmer or cooler than surrounding tissue.

