

**TITLE: Health literacy in pressure injury: findings from a mixed methods study of community-based patients and carers**

**Authors:** Lisa A. Durrant<sup>1</sup>, James Taylor<sup>1</sup>, Helen Thompson<sup>1</sup>, Kim Usher<sup>1,2</sup>, Debra Jackson<sup>1,3,4,5</sup>

1. Oxford Institute for Nursing, Midwifery & Allied Health Research (OxINMAHR), The Colonnade, Oxford Brookes University, Oxford, UK
2. University of New England, Australia.
3. Oxford University Hospitals NHS Foundation Trust, Oxford, UK.
4. Oxford Health NHS Foundation Trust, Oxford, UK.
5. University of Technology, Sydney, Australia

**Ethics details (will be inserted into paper following peer review process):**

Number: 16/NE/0075 The Proportionate Review Sub-Committee of the North East -Newcastle & North Tyneside 1 - Research Ethics Committee

**Contributions**

We assert that all authors meet the criteria for authorship having participated sufficiently in the work.

**TITLE: Health literacy in pressure injury: findings from a mixed methods study of community-based patients and carers**

**ABSTRACT:**

This paper, drawn from a larger mixed methods case study, provides insights into the health literacy of community-based patients with pressure injuries, and their carers, and critically analyses the patient information resources available; crucial because health literacy is associated with patient care and outcomes for patients. Two data sets were used to better understand patient literacy in relation to pressure injury: (i) narratives from patients and carers; and, (ii) analysis of patient education resources. Narratives were subject to content analysis and patient education resources available to the patients were analysed drawing on the Simplified Measure of Gobbledygook, the National Health Service Toolkit for Producing Patient Resources and compared to an internationally advocated pressure injury leaflet. Study findings indicated that despite leaflets broadly meeting required production and content guidelines, patients appeared to poorly engage with these materials and demonstrated limited health literacy in relation to pressure injury. Although improvements in leaflet production and readability may be advantageous, emphasis should remain on quality patient-healthcare professional relationships, to enable tailored patient education that can enhance awareness and engagement with treatment and prevention interventions.

**Keywords:** pressure injury, health literacy, community care, patient information, patient safety, mixed methods

**Introduction**

Pressure injuries (PI) can be defined as localised injury to the skin and/or underlying tissue, and whilst their aetiology is multi-factorial, they typically develop over a bony prominence as a result of pressure or pressure and shear in combination (National Pressure Ulcer Advisory Panel et al. 2014). Not only do PI cost health services significant amounts of money annually (National Institute for Health and Care Excellence 2014a), they have profound impacts on patient and family wellbeing (Latimer et al 2014; XXXX blinded for peer review). Engaging patients, families and carers in prevention is essential if the burden of PI is to be eliminated or reduced. The ability of patients and carers to understand the causes and implications of pressure damage are crucial to effective engagement. The concept of health literacy has emerged over the past three decades, and while there are debates around the concept, there is not a universally agreed definition of health literacy, with scholars theorising distinctions between:

functional health literacy – that is, the ability to read and understand written information and instructions; communicative or interactive health literacy – a more advanced form of cognitive, literary and social skills; and, critical literacy, in which people are able to apply a range of skills to critically analyse information and use this to improve personal autonomy over their health (Nutbeam 2000, Institute of Medicine 2004, Sykes et al. 2013). Effective health literacy has been associated with the formation of effective partnerships between patients, carers and health professionals (Nutbeam 2008), and considered to be essential to promoting optimal health (Berkman et al. 2011). Health literacy is promoted by a range of strategies, including the provision of informative materials, and delivery of verbal information and expert advice in timely fashion. Provision of informative materials could be used to both improve knowledge about health issues and to accommodate low health literacy. However, to be optimally effective, the delivery of health information to enhance health literacy needs to be tailored to meet the needs of individual patients, and so it is important to garner information about current knowledge and understandings related to a particular health issue and also to examine the current information available to patients. In this paper, we report a mixed methods study that aimed to generate information about health literacy related to PI in community dwelling patients living in their own homes, rather than in hospital.

## **Literature review**

Aetiological causes of PI create an ideal opportunity to foster increased health literacy because patient instigated interventions are fundamental to both the prevention and optimal healing of PI. The National Institute for Health and Care Excellence (2015) acknowledge that the majority of PI preventive care will take place within patients' own homes and emphasise the importance of PI patient education, specifically advocating persons at high risk of developing PIs be provided with information regarding signs of PIs, potential implications for quality of life and what people can do to prevent PI (National Institute for Health and Care Excellence (2014b). The SSKIN care bundle (an acronym for Surface, Skin inspection, Keep moving, Incontinence, Nutrition) is a five step model for pressure ulcer prevention, adopted by NHS improvement and advocated across many UK-based National Health Service Trusts (NHS Midlands and East 2012). It encompasses multiple interventions that may require autonomous patient implementation on a daily basis (Well 2012), for example, regular (self) repositioning to avoid excessive localised pressure resulting in ischemia-reperfusion injury (Gillespie et al. 2014). In addition, maintenance of adequate nutrition and hydration are promoted to support skin preservation and optimise PI healing (Posthauer et al. 2015). Regular skin inspections are also recommended to detect early signs of skin damage or deterioration (Duncan 2007). Achieving these interventions may be dependent on patients' knowledge of PIs and their understanding of why such

actions are significant to PI prevention, emphasising the need for effective and targeted methods of patient education.

Although any patient may develop a PI, persons aged over 70 are the most susceptible to PI (Landi et al. 2007); and so it is important that patient information on PI prevention is developed in a way that engages all groups in the community. Thus, community literacy is an issue. It is reported only 56% of 16-65-year olds achieved GCSE (General Certificate of Secondary Education) or equivalent English qualifications (Harding et al. 2012), whilst 20% of UK adults are reportedly functionally illiterate (World Literacy Foundation 2015). Therefore, age and community literacy must be taken into account when preparing patient information materials. Examination of patient literature exposes its potential lack of readability, typically using language requiring a high-school level reading age, alongside variability in typeface sizes and quality of presentation, all contributing to reduced readability (Wilson & Williams 2003, Fitzsimmons et al. 2010; Williams et al. 2016), potentially reducing the ability of older people to effectively engage with this material. People for whom English is a second language may also find it more difficult to engage with patient information resources around PI. Collectively, the current status of education materials may fail to comply with National Institute for Health and Care Excellence (NICE) pressure injury prevention guidance, in which tailored information should be provided regarding causation, signs of PI development and preventive actions (National Institute for Health and Care Excellence 2014b).

### **Study Aim**

The aim of this paper is to provide information into the health literacy of community-based patients with PI; and to critically analyse whether patient information resources, routinely provided as leaflets to patients with PI, or at high risk of PI, informs their understanding of PI. Two data sets were used in this study: (i) narratives from patients and carers; and, (ii) analysis of patient education resources.

### **Methods**

This paper is drawn from a larger ethically approved mixed-methods case study that sought to explore the burden of pressure injuries within a local culturally diverse community defined by a single postcode area. In the larger study, a simultaneous mixed-methods design was used whereby quantitative and qualitative data were collected separately but combined during the interpretation stage to reach a final understanding (Kenkyu 2014). Quantitative data; demographic information, general medical information and PI specific information, was sourced from the medical records of the community nursing teams providing care to PI patients in the case study area in 2015. To protect individual identities, these

routinely collected data were anonymised before access by the research team for analysis. Qualitative accounts, reported according to the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al. 2007), from participants and carers/families members from the case study area were used to enrich the quantitative dataset. Findings pertaining to the demographics of the community, characteristics of the PI participants, their experiences of pain, service use and equipment provision have already been reported (XXXX blinded for peer review). In keeping with the larger study, this current aspect of the study involved two phases and two distinct data sets that were collected simultaneously. The first data set drew on narratives from patients and carers identified in the qualitative aspect of the larger study. The other data set involved analysis of patient information material on PI routinely provided to patients in the target postcode area and compared to a leaflet produced by the overarching European Pressure Ulcer Advisory Panel (EPUAP). All participants who provided narratives had received PI related health care from both the acute and community health services in the target area and received leaflets A and B as paper copies.

***Narratives from patients and carers:*** To be included in the qualitative part of the study, participants were required to be aged 18 or over, currently receiving or just completed treatment for PI with the capacity to understand and consent to participate in the study. Patients receiving end of life care were excluded. Over 23 weeks (May- October 2016), 36 potential participants, identified by hospital and community tissue viability and podiatry services or district nursing teams, were given the study information by their nurses at routine health appointments. Potential participants were encouraged to discuss the study with friends, family and GP's then contact the research team voluntarily with a reply slip and pre-paid envelope. Thirteen participants were recruited to the overall study, 12 were included in this paper as only participants with experience of living with PI in their own homes were analysed, excluding a single participant with only hospital-based PI experience. Reasons for non-participation were not recorded due to the voluntary nature of recruitment.

For consistency, participants were all interviewed in English by the same experienced postdoctoral female health professional (XX); a translation service was offered but not required. Participant's selected a place for interview, nine were held at participant's homes, three in hospital to coincide with other health appointments and including one inpatient, hospitalised for reason other than PI but with considerable experience of PI at home. In accordance with the patient's wishes, five family members and carers were also invited to consent and participate. The interviewer had no previous association with the participants and built rapport during the pre-interview discussion and completion of the EQ-5D® health status questionnaire (with permission, EuroQol Group 1990). Semi-structured interviews

lasted an average of 37 minutes (range 16-69 minutes). To ensure coverage of the same topics, an interview guide was used that was devised by the research team with input from a previous PI sufferer (diCicco-Bloom & Crabtree 2006). Open ended questions were used to ascertain if the patients recalled the provision and content of leaflets including, "What types of information have you been given regarding PI?" and "have you read any information about PI and its prevention?" were used as well as questions relating to patients understanding of why their PI had developed.

**Analysis of participant narratives:** Audio recordings of the interviews were transcribed verbatim and content analysis was performed by three experienced qualitative researchers (XX, XX, XX). An approach informed by content analysis (Watson et al. 2008) was used to systematically harvest the narrative to uncover information pertaining to patient and carer literacy around PI.

**Analysis of patient education resources:** Three patient leaflets were analysed in their PDF formats. Leaflets A and B comprised of currently available leaflets provided from a community and acute hospital NHS trusts within the same county as the study's participants. Leaflet A was provided to patients on discharge from the acute hospital via the tissue viability service, leaflet B was provided to community patients by district nurses to patients with PI or at high risk of PI. Both A and B, could also be accessed via the internet. Leaflet C was produced by an international pressure injury advisory panel, which encompassed the study region, freely available via the internet but not provided in paper copy to patients, Readability of each leaflet was analysed by calculating their SMOG (Simplified Measure of Gobbledygook) score (McLaughlin 1966). These scores are predominantly influenced by the number of polysyllabic words among the total number of sentences. Although various readability formulas exist, SMOG has been shown to demonstrate greater accuracy compared to other available measures and is endorsed by the Royal College of Physicians of Edinburgh (Fitzsimmons et al. 2010).

To assess compliance with national guidelines for producing patient materials, such as the use of headings and short sentences, leaflets were appraised against the NHS tool for producing patient literature (Department of Health 2003). No pre-existing tool was available to achieve this, therefore a simple Likert scale measure was created containing both general criteria applicable to all patient literature, such as typeface and the use of bullets or numbers, and those specific for condition-related information such as causes of PI (see supplementary material). Compliance with individual criteria was collated into categories and compliance scores. Allowances were made for leaflet C due to its international usage, such as discounting the requirement of an NHS logo. Additionally, leaflets were read to assess whether they contained PI specific information including preventive actions advised

within the SSKIN care bundle. The total number of images in the leaflets were counted and described to ascertain their relevance to PI or its prevention.

## Results

In presenting the results, we first present the findings of the content analysis, followed by the findings pertaining to the patient information material, and then we draw the two together to synthesise the two data sets. Participants (n=12) ranged in age from 31 - 92 and had lived with PI for periods ranging from 2 months – 20 years. 3 were male, and 9 female, and 11 were white British, with the other participant being from the black minority ethnic (BME) community. Overall our participants showed little insight and understanding into the causes of their PI. A contrast between patients' limited understanding of PI and the availability of good quality PI leaflets was evident. Both of the NHS leaflets examined showed generally good compliance with NHS guidelines regarding design and content; however, the reading level of the leaflet was higher than the recommended level, meaning that patients and carers may not be able to fully understand the information. Participants did not receive specific participant information about their PI for this study. All had been living with PI for some time prior to participation in the study and had received information from their regular health providers. We wanted to ascertain their current knowledge into their condition. In presenting excerpts of narrative, we provide the gender, age and duration of the PI in brackets.

**Patient and carer narratives:** Through their narratives, participants revealed issues and concerns with health literacy in relation to PI. Despite having a PI for considerable periods of time, participants generally expressed low levels of insight and understanding into the causes and nature of PI. While some participants showed some understanding; *'it's pressure from an outside element that causes the problem'* (participant 12; f80, PI for 3 months); others had little idea of why or how they had got a PI and when asked, expressed bewilderment, *'no idea, I have no clue about it and that's the whole bloody truth... no idea'* (participant 6; m83, PI for 6 months). Others felt they had some knowledge of the causes, *'it's caused by hard skin forming on the feet, and the hard skin, well causes problems'* (participant 3; m75, PI for 12 years). When asked what they thought caused a PI, participant two stated, *'basically, is it like getting a red mark and feeling it's like maybe going hot? Could it be something like that?'* (participant 2; f31, PI for 20 years).

However, even where good quality information was available to participants, they could be quite passive in relation to engaging with information available. Some participants chose to not engage with

the patient information material, expressing the view that it was more the responsibility of carers to concern themselves with such matters.

*“there’s plenty of information leaflets if I want to take them, which I don’t, because I leave the girls [health professionals] to deal with it and they know what they’re doing”* (participant 3; m75, PI for 12 years).

A few of the participants indicated they had actively sought to use other sources of information, but this information did not always meet their needs, and so they chose not to engage with it. One carer commented, *‘I’ve looked on Google, ... some of the pictures [of PI] were horrifying’* (carer of participant 2). It may have been that the sites accessed by the care of participant 2 were more aimed to a professional audience. Information that was too medically-focused did not meet the needs of our participants, with one commenting *“I do not understand”* (participant 6; m83, PI 6 months) when provided with patient leaflets containing medical information.

While some participants revealed some accurate knowledge about the nature of PI, a range of views about causation were revealed. Participant 10 felt the usual causative factors for PI did not apply to her – rather her view was that her own unique situation and set of circumstances were responsible. In this way, participant 10 revealed she viewed her health much more holistically.

*Well, it’s like where you’ve been sitting too long, but I don’t put mine to that because I wasn’t sitting all the time. I put mine down to my general health because I’d lost so many people in the last few years and I’d never grieved* (participant 10; f76, PI 14 months).

Participant five expressed some good insights into the causes of PI but hadn’t realised that they could affect anyone, given the right set of circumstances. Prior to getting his PI, he had in no way considered this was an issue that could affect a man of his age and physical condition.

*Well, I think when people talk about pressure injuries we always tends to refer to them as elderly people in bed and can’t move themselves round. ... I’ve sort of realised, with having a pressure injury which I’ve got, which was ... during the suffering of a complete mental and physical breakdown, where I collapsed... I fell. One of my legs was twisted up ... trapped, been pushed on a sharp corner and it’s this particular incident with the heel being jammed on a sharp corner for so long that is responsible for the problems I’m suffering now* (participant 5; m62, PI 6 years).

**Analysis of patient education resources** (see table 1): Readability of NHS trust leaflets showed consistency with SMOG scores of 15.7 among leaflets A and B; Leaflet C produced by the pressure



injury advisory panel displayed reduced readability with a SMOG score of 17.1 and the highest polysyllabic word count of 72 words. However, all leaflets' readability scores were considerably higher than the target SMOG score of 9.0.

**Table 1: Leaflet analysis**

<b>Criteria</b>	<b>Leaflet A</b> Community Health Trust	<b>Leaflet B</b> Acute Hospital Trust	<b>Leaflet C</b> Pressure Injury Advisory Panel
<b>Compliance with general leaflet guidelines from the NHS toolkit (see supplementary material)</b>	39(85%)	44(96%)	28(64%)
Design Principles	8(100%)	8(100%)	3(38%)
Paragraphs	14(100%)	14(100%)	10(71%)
Typeface	4(100%)	4(100%)	3(75%)
Front cover	6(100%)	6(100%)	4(100%)
Back cover	4(50%)	6(75%)	4(50%)
Other	3(50%)	6(100%)	4(67%)
<b>Compliance PI specific guidelines (see supplementary material)</b>	7(88%)	8(100%)	4(50%)
Reference to SSKINS	Yes	Yes	No
<b>SMOG score</b>	15.7	15.7	17.1
Word Count	693	785	661
Number of Sentences	73	84	29
Number of Polysyllabic Words	42	48	72
<b>Total Number of Images</b>	2	4	1
<b>PI Image Count</b>	0	2	0
<b>Image Description</b>	Front Cover: Pressure relieving cushion.	Front Cover: Grey geometric shapes	Front Cover: Red geometric shapes

	Diagrammatic body map of pressure points	Grade 1 PI on heel Deep tissue injury on unidentifiable body part. Diagrammatic body map of pressure points	
--	--	---	--

Compliance with the general leaflet guidelines from the NHS Toolkit (2003) for producing patient literature criteria varied among NHS trust leaflets; leaflet A displayed 85% compliance meeting all general criteria excluding the signposting of additional suitable patient resources, additionally not including a copyright notice on its back cover. Leaflet B exhibited 96% compliance meeting all criteria apart from a copyright notice. Leaflet C showed markedly less compliance of 64%, with allowances for NHS specific criteria e.g. NHS logo inclusion, owing to failing to meet criteria regarding typography and paragraph structure, specifically, identifiable headings and poor text to background contrast were found. Additionally, patient instructions regarding seeking clinical support were not always justified with an explanation. Usage of the SSKINS care bundle was present in leaflets A and B, its absence in leaflet C may reflect the leaflet's international usage. PI specific compliance scores exhibited similar variation, leaflet B achieved 100% compliance and leaflet A scored 88%, meeting all criteria excluding that requiring other implications of pressure injuries to be included, for example, lifestyle implications. Conversely, leaflet C achieved 50% compliance due to failing to include information regarding early signs and symptoms, patient instigated preventive interventions and pressure injuries' broader holistic implications.

Analysis of images and diagrams exposed inconsistencies between leaflets. A mean average of two images or diagrams was found, with broad variances in total count and types of imagery among the leaflets (range 1 - 4). Only Leaflet A included a PI related front cover image, however, did not include any images of PI (see table 3). Leaflet B did include two images of PI, only one of these images could be identified to a specific anatomical location. Both leaflet A and B included a diagrammatic depiction of typical anatomical pressure points. Leaflet C included no images of PI or diagrams beyond its front cover.

## Synthesis of findings

Insights from the participant narrative revealed patients had limited understandings into the reasons they had developed a PI, despite having access to patient information leaflets. Their health literacy was poor – not only did they display low functional health literacy; they did not reveal communicative/interactive or critical health literacy. Generally, their knowledge and understanding of PI were not enhanced by the availability of patient information leaflets. Due to the numerical approach used to assessing the readability of leaflets, participants were not directly able to remark on the readability of the leaflets they had been provided. However, the ability of participant's ability to engage with these leaflets was potentially hindered by their poor readability scores with all three leaflets above the target score. Specific aspects could have been improved, such as contextualising PI signs and symptoms into their effects of PI on daily living. Equally, all leaflets failed to include information relevant to people with darkly pigmented skin. Terms referring to key early warning signs of PI such as blanching or skin redness may be irrelevant in darker skin tones and suggests assumptions that everyone has white skin and potentially disengages some people. Indeed, in our current study, one participant was from a black background, and this participant (participant 6) expressed very little understanding as to the genesis of his PI. This may not have felt the informational material was relevant to his own situation, given the lack of inclusion of people of colour in the informational leaflets available to him.

## **Discussion**

Our findings suggest leaflets alone play a minor role in improving patients PI health literacy as reflected in their knowledge and engagement with preventive measures. Previous studies have proposed similar notions, finding providing patient materials in clinical environments was not an effective method of PI education or improving adherence to preventive interventions (Latimer et al. 2014, Schoeps et al. 2017). Instead, it was suggested focus should be placed on improving patient-healthcare professional relationships and enhanced verbal dialogue regarding these topics.

Variability in ensuring patient literature utilised met both readability and design guidelines may have instigated greater false-negative results regarding improved patient knowledge and information retention (Wilson & Williams 2003, Hartigan et al. 2012, Vowden 2015). Longitudinal studies examining patients' retention of PI prevention information have not extended past one week, limiting the understanding of knowledge decay (Vowden et al. 2015, Hartigan et al. 2012). Additionally, these studies may have been confounded by inconsistencies between participants individual usage of materials provided, with neither study providing measurements regarding the frequency or duration that materials were available or whether it was actually read (Vowden et al. 2015, Hartigan et al. 2012). Establishing patient materials readability is hindered by readability formulas focus on the number of

polysyllabic words. Consequently, patient materials readability may be underestimated due the common presence of polysyllabic words in health care vocabulary (Graham et al. 2015).

Furthermore, broader questions can be raised over the practicality of many preventative interventions being completed by older persons. Adequate nutrition is fundamental to skin preservation and optimal healing durations (Posthauer et al. 2015). However, in the UK an estimated 1.3 million persons (8%) aged over 65 suffer from malnutrition (Russel & Elia 2014); it is estimated that nearly 1 million persons in this age group reduce food expenditure due to rising utility costs (Age UK 2017). Regular skin inspection is advocated to monitor for skin deterioration, despite 35% of persons over 75 stating their visual impairment hinders daily tasks (RNIB 2015). It is estimated that 49% of this demographic live alone, meaning they may not have anyone readily available to assist with skin inspections (Office for National Statistics 2015). Such statistics may suggest the current universal approach to preventative measures fails to consider limitations present among those most susceptible to PI in the community. The clinical significance of these findings suggests the need for required alterations in the current approach to improving patients' understanding of PI and facilitating their proactive role in PI prevention. Patient materials should remain subsidiary rather than a substitute to verbal conversations regarding these topics; and the conversations need to occur in a manner tailored to the individual. Equally, emphasis should be placed on healthcare professions assessing patients' PI knowledge and ability to implement preventive measures over the duration that care is provided. Focus should also be placed on ensuring persons with physical limitations receive adequate support to complete preventive measures such as skin inspection.

Whilst this paper provides a previously unexplored combination of interviews with persons living with PIs and analysis of the leaflets they had been provided, further research is required to evaluate PI prevention indices and improve adherence with preventive measures. Insights gained from older persons regarding their ability to instigate preventive measures may enhance the understanding of their suitability and current adherence. Equally, establishing the frequency to which PI patient materials are provided and the extent to which they are utilised may enable greater comprehension of their current influence on PI prevention. Lastly, examining the duration to which patients retain PI knowledge may help influence the nature and frequency to which education methods are utilised.

### **Strengths and limitations of the study**

The strength of the study lies in the exploration of PI and PI prevention from the community dwelling patient's perspective rather than that of care providers or health professionals. The limited number of

leaflets analysed may provide an incomplete account of the quality of materials available to patients with PI and their carer's, additionally the use and value of verbal PI information or sources derived from the internet was not evaluated. Such analyses would have been difficult to assess and quantify, due to a lack of formal guidelines or methods for recording such conversations in the written notes, yet their impact on PI understanding may have been considerable. The reading ability of the interviewees was not assessed and although a wide age range was represented, the low number of participants may not be representative of the wider population of PI sufferers. The leaflets were evaluated by the same author to provide rigour (XX), as although SMOG scores are formulaic, other aspects still required subjective judgement for scoring and interpretation. Consistency in interviewing and the similarities in the responses of the participants suggest that the lack of understanding regarding PI was a real phenomenon.

## **Conclusion**

Our findings provide information suggesting that patient literacy in relation to PI was poor in this group. However, questions as to how to best provide needed information that patients can meaningfully engage in remains. It is unknown from this study whether the low level of functional health literacy in relation to PI knowledge amongst these patients was due to not being provided with formal patient education opportunities. Whilst PI patient materials may be an adjunct to verbal dialogue with patients to enhance their knowledge and involvement in preventive measures, their meaningful contribution may be questioned. Our findings indicate that despite being provided with leaflets patients appeared to engage poorly with these materials and demonstrate a limited comprehension of PI's causes, signs and associated preventive measure. Difficulties remain in establishing the specific contribution PI leaflets make to reducing PI indices and improving PI healing due a limited and often flawed evidence base. Although improvements in leaflet production and its content's readability may be advantageous, emphasis should remain on improved patient-healthcare profession relationships, enabling tailored patient education to enhance awareness and engagement with treatment and prevention interventions.

## **References**

Age UK (2017). *Later Life in the United Kingdom - August 2017*. Retrieved from [http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later\\_Life\\_UK\\_factsheet.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true)

Berkman. N.D, Sheridan. S.L, Donahue. K.E, Halpern D.J, Crotty. K (2011). Low Health Literacy and Health Outcomes: An Updated Systematic Review. *Ann Intern Med.* 155 (2), 97-107.

- Clarke Moloney, M., Moore, A., Adelola, O. A., Burke, P. E., McGee, H., & Grace, P. A. (2005). Information leaflets for venous leg ulcer patients: are they effective?. *Journal of wound care*, 14(2), 75-77.
- di-Cicco-Bloom, B. & Crabtree, B.F. (2006). The qualitative research interview. *Medical Education*. 40(4): 314–321.
- Department of Health (2003). *Toolkit for producing patient information*. Department of Health. London, HMSO.
- Duncan, K. (2007). Preventing Pressure Ulcers: The Goal Is Zero. *The Joint Commission Journal on Quality and Patient Safety*, 33(10), pp.605-610.
- EuroQol Group (1990). EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy* 16(3):199-208.
- Fitzsimmons, P., Michael, B., Hulley, J. and Scott, G. (2010). A readability assessment of online Parkinson's disease information. *The Journal of the Royal College of Physicians of Edinburgh*, 40(4), pp.292-296.
- Gillespie, B., Chaboyer, W., McInnes, E., Kent, B., Whitty, J. and Thalib, L. (2014). Repositioning for pressure ulcer prevention in adults. *Cochrane Database of Systematic Reviews*. 3(4). doi: 10.1002/14651858.CD009958.pub2
- Graham, C., Reynard, JM. & Turney, BW. (2015). *Consent information leaflets – readable or unreadable?* *Journal of Clinical Urology*, 8(3): 177–182.
- Harding, C., Romanou, E., Williams, J., Peters, M., Winkley, J., Burke, P., Hamer, J., Jeram, K., Nelson, N., Rainbow, B. and Bond, B., (2012). The 2011 Skills for Life Survey: a survey of literacy, numeracy, and ICT levels in England. 2012. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/36000/12-p168-2011-skills-for-life-survey.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/36000/12-p168-2011-skills-for-life-survey.pdf)
- Hartigan, I., Murphy, S. and Hickey, M. (2012). Older adults' knowledge of pressure ulcer prevention: a prospective quasi-experimental study. *International Journal of Older People Nursing*, 7(3), pp.208-218.
- Institute of Medicine (2004). *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academies Press.
- Kenkyu K. (2014). Mixed methods in nursing research: An overview and practical examples. *The Japanese Journal of Nursing Research*. 47(3), 207-217.
- Landi, F., Onder, G., Russo, A., & Bernabei, R. (2007). Pressure ulcer and mortality in frail elderly people living in community. *Archives of gerontology and Geriatrics*, 44, 217-223.
- Latimer, S., Chaboyer, W. and Gillespie, B. (2014). Patient participation in pressure injury prevention: giving patient's a voice. *Scandinavian Journal of Caring Sciences*, 28(4), pp.648-656.
- Longtin, Y., Sax, H., Leape, L. L., Sheridan, S. E., Donaldson, L., & Pittet, D. (2010, January). Patient participation: current knowledge and applicability to patient safety. In *Mayo Clinic Proceedings* (Vol. 85, No. 1, pp. 53-62). Elsevier.

McInnes, E., Chaboyer, W., Murray, E., Allen, T. and Jones, P. (2014). The role of patients in pressure injury prevention: a survey of acute care patients. *BMC Nursing*, 13(1). 41. doi.org/10.1186/s12912-014-0041-y

McLaughlin, G. H. (1969). SMOG grading-a new readability formula. *Journal of Reading*, 12(8), 639-646.

National Health Service Improvement (2013). *Classic Thermometer Dashboard*. Available at: [https://www.safetythermometer.nhs.uk/index.php?option=com\\_dashboard&view=dashboard&id=5&Itemid=137](https://www.safetythermometer.nhs.uk/index.php?option=com_dashboard&view=dashboard&id=5&Itemid=137).

National Health Service Midlands and East (2012). Five simple steps to prevent and treat pressure ulcers. Available at [nhs.stopthepressure.co.uk/docs/1352365192\\_GHqH\\_sskin\\_graphic.jpg](https://nhs.stopthepressure.co.uk/docs/1352365192_GHqH_sskin_graphic.jpg)

National Pressure Ulcer Advisory Panel, European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance (2014). *Prevention and Treatment of Pressure Ulcers: Quick Reference Guide*. Emily Haesler (Ed.). Cambridge Media: Osborne Park, Australia.

National Institute for Health and Care Excellence (2014a). *Costing Statement: Pressure Ulcers. Implementing the NICE Guideline on Pressure Ulcers*. Clinical Guideline No. 179. National Institute for Health and Care Excellence. Retrieved from <https://www.nice.org.uk/guidance/cg179/resources/costing-statement-pdf-248688109>

National Institute for Health and Care Excellence (2014b). *Pressure ulcers: prevention and management*. National Institute for Health and Care Excellence. Retrieved from <https://www.nice.org.uk/guidance/cg179>

National Institute for Health and Care Excellence (2015). Quality Statement 7: Information on preventing pressure ulcers. National Institute for Health and Care Excellence. Pressure Ulcer: Quality Standard QS89. Retrieved from <https://www.nice.org.uk/guidance/qs89/chapter/Quality-statement-7-Information-on-preventing-pressure-ulcers>

NHS Digital (2017). *NHS Safety Thermometer: Patient Harms and Harm Free Care. England March 2016 – March 2017*. Health and Social Care Information Centre. Leeds. Retrieved from <http://content.digital.nhs.uk/catalogue/PUB23624/nati-safe-rep-mar-2016-mar-2017.pdf>

Nutbeam, D (2008). The Evolving Concept of Health Literacy. *Social Science and Medicine*. 67 (12), 2072-2078.

Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21<sup>st</sup> century, *Health Promotion International*, 15(3), 259-267.

Oozageer Gunowa, N, Hutchinson, M, Brooke, J. & Jackson, D. (2017). Pressure injuries in people with darker skin tones: A Literature Review, *Journal of Clinical Nursing*. doi: 10.1111/jocn.14062

Office for National Statistics (2015). *Labour Force Survey*. Office for National Statistics.

Posthauer, M., Banks, M., Dorner, B. and Schols, J. (2015). The Role of Nutrition for Pressure Ulcer Management. *Advances in Skin & Wound Care*, 28(4), pp.175-188.

Reid, J., Klachko, D., Kardash, C., Robinson, R., Scholes, R. and Howard, D. (1995). Why people don't learn from diabetes literature: influence of text and reader characteristics. *Patient Education and Counseling*, 25(1), pp.31-38.

RNIB (2015). *Living with sight loss - Updating the national picture*. RNIB. Retrieved from <https://www.rnib.org.uk/sites/default/files/Living%20with%20Sight%20Loss.pdf>

Russell, C. A., & Elia, M. (2014). Nutrition screening surveys in hospitals in the UK, 2007–2011. *British Association for Parenteral and Enteral Nutrition*. Retrieved from <http://www.bapen.org.uk/pdfs/nsw/bapen-nsw-uk.pdf>

Schoeps, L. N., Tallberg, A. B., & Gunningberg, L. (2017). Patients' knowledge of and participation in preventing pressure ulcers—an intervention study. *International Wound Journal*, 14(2), 344-348.

Sykes, S., Wills, J., Rowlands, G., & Popple, K. (2013). Understanding critical health literacy: a concept analysis. *BMC Public Health*, 13, 150. <http://doi.org/10.1186/1471-2458-13-150>

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32 item checklist for interviews and focus groups. *International Journal for Quality in Healthcare*, 19(6), pp.349-357.

Vowden, K., Warner, V. and Collins, J. (2015). Pressure Ulcer Incidence: Do patients retain information? *European Wound Management Association*, 16(1), pp.35-36.

Watson, R., McKenna, H., Cowman, S. & Keady, J. (2008). *Nursing Research Design and Methods*, Churchill Livingstone, Edinburgh.

Well, E. (2012). SSKIN – the care bundle that puts the emphasis on prevention. *Nursing Standard*, 27(9), pp.18-18.

Williams, A., Muir, K. and Rosdahl, J. (2016). Readability of patient education materials in ophthalmology: a single-institution study and systematic review. *BMC Ophthalmology*, 16(1).133 doi: 10.1186/s12886-016-0315-0

Wilson, F. and Williams, B. (2003). Assessing the readability of skin care and pressure ulcer patient education materials. *Journal of WOCN*, 30(4), pp.224-230.

World Literacy Foundation (2015). *The Economic & Social Cost of Illiteracy: A snapshot of illiteracy in a global context*. World Literacy Foundation. Retrieved from <https://worldliteracyfoundation.org/wp-content/uploads/2015/02/WLF-FINAL-ECONOMIC-REPORT.pdf>

### Supplementary Information:

Scoring System:

0 - Non-compliant / not-present.

1 - Partially compliant / Inconsistently applied

2 - Fully compliant / consistency applied

Design Principles	
Compliance Score	
No writing over background images or design	
Use Only 1-2 colours	



Light background with dark print / Dark background with white print	
Diagrams or pictures	
<b>Paragraphs</b>	
<b>Compliance Score</b>	
Clear headers (Larger font or bold text)	
Avoids using words in capital letters (bold lettering used instead)	
Short sentences (15-20 words) (Random sample of five from start, middle and end)	
Bulletpointed or numbered points	
Small blocks of text	
Question and answer format (breaks up large text bodies)	
Numbers (1-9 in words or >=10 in numbers)	
Align text left	
<b>Typeface</b>	
<b>Compliance Score</b>	
Typeface (Medium weight San Serif)	
Light background with dark print / Dark background with white print	
<b>Front cover</b>	
<b>Compliance Score</b>	
NHS Logo or NHS logotype (0 or 2)	
Title of leaflet (0 or 2)	
Associated department or directorate (0 or 2)	
<b>Back cover</b>	
<b>Compliance Score</b>	
Website address (0 or 2)	
Date of publication (0 or 2)	
Leaflet code (0 or 2)	
Copyright note (0 or 2)	
<b>Other</b>	

<b>Compliance Score</b>	
Question and answer format (breaks up large text bodies)	
Instructions with explanations	
Mentions other information sources or resources available (0 or 2)	

<b>PI Information Compliance Criteria</b>	
<b>Compliance Score</b>	
What are causes of PI	
Does anything increase the risk of PI? E.g. age, sex, ethnicity, family history	
Signs and symptoms of PI	
Test or examinations for PI	
What are the next steps	
What can patients do for themselves	
Other implications e.g. infecting other people	
Who can they contact if they have any questions	
Say where the patient can find further information e.g. websites or support groups	