

## Older people's experiences of dignity and nutrition during hospital stays: Secondary data analysis using the Adult Inpatient Survey

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### Introduction

The report uses the Adult Inpatient Survey 2012 to build up an in-depth quantitative evidence base on older people's experiences of dignity and nutrition during hospital stays in England. The survey covers adults aged 16 or above who stay in hospital for at least one night. The research has been funded by the Economic and Social Research Council, Research Grant ES/K004018/1.

### Main findings

- There was a widespread and systematic pattern of inconsistent or poor standards of care during hospital stays in England in 2012. Patient experiences of inconsistent or poor standards of dignity and help with eating do not appear to be limited to isolated "outlier" providers. Rather, this appears to be a significant general problem affecting the vast majority of NHS acute hospital trusts.
- In 2012, about a quarter of all survey respondents indicated that they needed help with eating during their hospital stay. This is a substantial proportion and points towards support with eating being relevant for significant numbers of inpatients – just under three and a half million each year - rather than being a marginal or specialist issue.
- Of those who needed help with eating, more than 1 in 3 (38%) report that they only sometimes received enough help with eating from staff, or did not receive enough help from staff. This is equivalent to around 1.3 million people on an annual basis, of whom about 640,000 are aged 65 or over.
- Amongst the population aged over 65, risks of inconsistent and poor standards of care were higher for women than for men, for individuals aged over 80 and amongst those who experience a limiting long-standing illness or disability such as deafness or blindness, a physical condition, a mental health condition or a learning difficulty, or an illness such as heart disease, stroke or cancer.
- Levels of inconsistent or poor standards of dignity and help with eating are too high in the vast majority of trusts. There has been remarkably little change in the percentage of individuals reporting inconsistent and poor standards of care over time.
- The quantity and quality of nursing care, and whether or not there is a choice of food, have a large, statistically significant, effect on the probability of experiencing poor standards of help with eating. These variables stand out as key potential policy levers for improving standards of care relating to meeting individual nutritional needs.
- Whilst there has been increasing public policy attention in this area following the Mid-Staffordshire Public Inquiry, ongoing public policy efforts will be required to ensure quality

improvement and that the new fundamental standards of care, which cover dignity and respect and help with eating, are implemented and enforced.

- Equality and human rights standards should be fully embedded into the arrangements for monitoring, inspecting and regulating healthcare. There is a need to move away from a “population average” approach, to systematic disaggregation and identification of “at risk” groups (for example, individuals aged 80 or above who experience a disability).
- Indicators of dignity and nutrition have an important role to play within the portfolio of indicators used to monitor the quality of healthcare. Judgements about the compliance of acute hospital trusts with fundamental standards of care should be based on the evaluation of absolute levels of inconsistent and poor care (a “minimum threshold approach”). A “deviation from average” approach risks under-identification of inconsistent and poor standards of care.

## **Prevalence of inconsistent and poor standards**

### **Dignity and respect**

- Poor or inconsistent standards of dignity and respect affected 23% of inpatients in England in 2012. This is equivalent to around 2.8 million people on an annual basis, of whom about 1 million are aged 65 or over.
- Of the total affected by poor and inconsistent standards of dignity and respect, 4% experienced poor standards of dignity and respect (reporting that they were not treated with dignity and respect) with the remainder experiencing inconsistent standards (reporting that they were treated with dignity and respect “sometimes”).

### **Help with eating**

- Poor or inconsistent standards of help with eating affected 38% of inpatients who needed help during their hospital stay in England in 2012. This is equivalent to around 1.3 million people on an annual basis, of whom about 640,000 are aged 65 or over.
- Of the total affected by poor and inconsistent standards of help with eating, 18% experienced poor standards of help with eating (reporting not receiving help from staff) with the remainder experiencing inconsistent standards (reporting that they received help from staff “sometimes”).
- Amongst those who reported only sometimes, or not, receiving enough help from staff, 28% were between 66 and 80 years old and a further 28% were aged over 80 . Around 63% experienced a LLID such as being deaf and / or blind and / or experiencing a physical or mental health condition, a learning difficulty, or a long-term illness such as HIV, stroke/heart disease or cancer.
- The prevalence of poor standards of help with eating was 21% amongst individuals who experience deafness or severe hearing conditions; 24% amongst those who experience blindness or are partially sighted; 20% amongst those who experience a longstanding physical condition; 28% amongst those who experience a learning difficulty; 26% amongst those who experience a mental health condition; and 17% amongst those who experience a long-standing illness.

### **Relative risks amongst the older population**

- Amongst the population aged over 65, reported experiences of poor or inconsistent standards of care were higher for women, for individuals aged over 80, and for those who experience a long-standing limiting illness or disability.

- Poor or inconsistent standards of dignity and respect affected approximately 28% of all women over 80 who experience a long-standing limiting illness or disability.
- Amongst those who needed help with eating, poor or inconsistent standards of help affected approximately 62% of women over 80 who experienced a long-standing limiting illness or disability.

### Trends over time

- **Trends 2004/5-2012.** Looking back over the medium term, there has been remarkably little change in the percentage affected by poor or inconsistent standards of dignity and help with eating over the period for which data is available.
- There were only very small, statistically non-significant differences in the percentage experiencing poor standards of dignity and respect in 2004 and 2012.
- There were only very small, statistically non-significant differences in the percentage experiencing poor standards of help with eating in 2005 and 2012.
- **Trends 2011-2012.**
- The percentage reporting poor standards of dignity and respect was 3.0% in 2011 and 2.9% in 2012 (unweighted comparisons). This very slight fall was not statistically significant.
- The percentage of those needing help reporting poor standards of help with eating fell from 18.5% in 2011 to 16.8% in 2012 (unweighted comparisons). This decline was statistically significant. This might be an indication of some improvement in the wake of recent policy initiatives.
- **Trends 2012-2013.** CQC analysis suggests that there was a statistically significant fall in the percentage reporting “sometimes” being treated with dignity and respect between 2012 and 2013. The percentage reporting “not” being treated with dignity and respect, and the percentages reporting “sometimes” or “not” being helped with eating, remained unchanged.

## Drivers and cumulative risks

### Focussing on poor standards of help with eating:

#### Drivers

- Logistic regression analysis suggests that after other factors are controlled for, the risk of not being helped with eating is significantly higher for women rather than men, for people who experience a disability (experiencing a long-standing condition which causes difficulties, compared to not experiencing such a condition) and for responses filled in by proxy (where the form is filled in by, or with the assistance of, a friend, family or professional, rather than solely by the inpatient themselves).
- The effect of age was found to be complex. The odds ratios observed for older age groups are less than one, suggesting that older people are less likely than younger people to report not receiving help. However, the trend by age should be interpreted in the context of evidence of “adaptive expectations”, whereby older people’s expectations are systematically lower than those of other groups. The odds ratio was found to be higher for over those aged 80 or above compared to intermediate age groups. The effect of disability on the probability of not being helped was also found to be strongest amongst those aged 80 or above.

- Perceptions of inadequate nursing quantity and quality, and lack of choice of food, stand out as having consistent, large associations with lack of support with eating during hospital stays.

### **Cumulative risks amongst individuals aged over 80**

- Model-based analysis suggests that the predicted probability of experiencing poor standards of help with eating for an individual over 80 who needs help but is “average” in other respects is 11%.
- The cumulative risks were found to be considerably higher for individuals who also experience a high risk individual “journey” through hospital (for example, staying in three or more wards or having a long stay); and amongst those who experience other aspects of poor care (for example, inadequate quantity / quality of nursing and no choice of food).
- For individuals who face all of these risk factors, the predicted probability of not receiving enough help with eating from staff during a hospital stay is estimated to be more than 90%.

### **Trust level findings**

- There was considerable variation in the scale of experiences poor standards of help with eating across hospital trusts. The percentage of those who needed help reporting not receiving help with eating from staff ranged from 5% to 34% in different acute hospitals.
- Based on a “deviation from average” approach, the percentage reporting poor standards of help with eating was found to be higher (statistically significant) than in the average trust in fifteen acute hospitals based on the full sample, or twelve acute hospitals, if the analysis is restricted to patients who needed help.
- Controlling for patient characteristics, their individual journey through hospital, and patient-reported quantity/quality of nursing substantially reduces the variation between hospital trusts – but some of these are factors over which the trusts have influence and arguably should not therefore be controlled for when making comparisons.
  - Based on a limited set of controls (for age, sex and route of admission only), three trusts had a higher percentage of poor standards of help with eating than the average trust (full sample) or two trusts if the analysis is restricted to patients who needed help.
  - Including controls for other factors mainly outside of a trust’s influence such as disability and length of stay further reduces the number of trusts which are identified as significantly different from the average trust.
  - With a full set of controls, including choice of food and quantity and quality of nursing, no trusts are identified as having a higher percentage of poor standards of help with eating than the average trust.
- Compared to an external target set at either 1% or 2%, rather than a target based on the performance of the average trust, levels of reported poor standards of help with eating were too high in the vast majority of trusts. The percentage of those who needed help reporting not receiving help with eating was higher (statistically significant) than 1% in all trusts and 2% in the vast majority of trusts.

## **Conclusions**

There was a widespread and systematic pattern of inconsistent or poor standards of care during hospital stays in England in 2012. Patient experiences of inconsistent or poor standards of dignity and help with eating do not appear to be limited to isolated “outlier”

providers. Rather, this appears to be a significant general problem affecting the vast majority of NHS acute hospital trusts.

### **Policy implications**

- Dignity and respect, and help with eating, are key markers of quality of care which have previously been under-recognized in public policy. Increasing policy attention in this area in the wake of the Mid Staffordshire NHS Foundation Trust Public Inquiry is a positive development.
- The Government has introduced new fundamental standards of care as part of its response to the Mid Staffordshire NHS Foundation Trust Public Inquiry. The findings in this paper reveal the magnitude and scale of the challenge ahead. Concerted and ongoing public policy efforts will be required to ensure that the new fundamental standards of care, which cover dignity and respect and help with eating, are implemented and enforced.
- The quantity and quality of nursing staff, and the availability of choice of food, stand out as key potential policy levers for improving standards of help with eating. Whilst these variables can be negatively affected by resource constraints, all three are within the control of hospital trusts to a certain extent.

### **Lessons for monitoring, regulating and inspecting**

- Equality and human rights standards should be further embedded into arrangements for monitoring, regulation and inspection. Risk assessment should move away from a “population average” approach, to systematic disaggregation and identification of “high risk” subgroups. Cumulative risks for specific population subgroups (for example, being over 80, experiencing a disability and being female) should be quantified.
- Indicators of dignity and nutrition have an important role to play within the portfolio of indicators used to monitor the quality of healthcare.
- Judgements about the implementation of fundamental standards of care, including the new minimum standards of dignity and nutrition, should take account of absolute levels of inconsistent and poor care prevalent within a hospital trust (a “minimum threshold” approach). A “deviation from average” approach (which focuses exclusively on a trust’s performance relative to the average trust) risks under-identifying inconsistent and poor performance.

### **Lessons for using patient experience data as a guide to public policy**

- Patient experience data provide an importance evidence base on standards of care. Better and more extensive use should be made of these data in the future.
- Interpreting older people’s self-reported experiences in healthcare is complex. The population over 65 is heterogeneous and large. Evaluation of older people’s experiences of healthcare should be based on narrow age band disaggregation, with separate identification and reporting of the risks facing the “oldest of the old”.
- Older people’s expectations of standards of care may be lower than those of other age groups. The phenomenon of ‘adaptive expectations’ should be explicitly recognized when using patient experience data as a guide to public policy.
- Feedback from family, friends and professionals, including proxy survey responses, can be particularly valuable in the context of evaluating older people’s experiences of care alongside responses from older people themselves.

- Efforts should be made to maximise older people's participation in patient feedback exercises. Support for older people filling in patient experience surveys and feedback forms should be increased.

## Notes

- The report uses the Adult Inpatient Survey 2012 to build up an in-depth quantitative evidence base on older people's experiences of dignity and nutrition during hospital stays in England. The survey covers adults aged 16 or above who stay in hospital for at least one night.
- In 2012 the survey had a total of 64,505 respondents from 156 trusts (a response rate of 49 per cent, rising to 51 per cent when adjusted for deaths).
- The dignity and respect question asks respondents: "Overall, did you feel you were treated with respect and dignity while you were in the hospital?". Response options are 1 "yes, always"; 2 "yes, sometimes"; 3 "no". The help with eating question asks respondents: "Did you get enough help from staff to eat your meals?". Response options are: 1 "yes, always"; 2 "yes, sometimes"; 3 "no"; 4 "I do not need help to eat meals". In this report, response 3 ('no') is interpreted as patient experience of a *poor* standard of care. An intermediate response (response 2, 'yes sometimes') is interpreted as patient experience of an *inconsistent* standard of care.
- Prevalence rates of patient experiences of poor and inconsistent standards of care are estimated using a new set of patient level weights. These provide estimates that are more clearly related to the national inpatient population than the unweighted data. Further details are set out in the main report. Trust level findings and findings over time are reported based on unweighted data.
- Trends over time are based on unweighted data. The cross-sectional estimates differ slightly from the weighted estimates. Further details are set out in the main report.
- Logistic regression modelling techniques are used to examine the drivers of poor standards of help with eating and to estimate cumulative risks for the over 80s. As is usual in the context of multivariate analysis, the statistical findings are limited in certain respects. These are set out in the main report.
- The report applies a new methodology for evaluating risk. This moves away from a "population average" approach and highlights the importance of systematic disaggregation and the identification of specific "at risk" groups.