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# A national census of care home residents

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## Abstract

**Background:** the medical and dependency characteristics of UK care home residents have not been well described. This undermines care commissioning, development and regulation. Data to inform policy and practice are needed.
**Objective:** to survey the dependency and clinical diagnoses of 16,043 people resident in the 244 care homes distributed across the UK managed by the largest provider of care in the UK.
**Results:** (i) Return rate of 97% (15,483 returns suitable for analysis). (ii) 25% were 'residential' and 75% in 'nursing' care. (iii) Medical morbidity and associated disability rather than non-specific frailty and social needs had driven admission in over 90% of residents. (iv) More than 50% of residents had dementia, stroke or other neurodegenerative disease. (v) Overall, 76% of residents required assistance with their mobility or were immobile. 78% had at least one form of mental impairment and 71% were incontinent. 27% of the population were immobile, confused and incontinent. (vi) Considerable overlap in dependency between residential and nursing care observed: only 40% of those in residential care were ambulant without assistance and 46% were incontinent.
**Conclusions:** the practicality of acquiring information on care home residents has been demonstrated. The care needs of people in care homes are largely determined by progressive chronic diseases. A single assessment and commissioning at the point of entry to care services is unlikely to address changing needs. Alternatives to institutional long-term care should only be considered in the context of current resident profiles, the practicality of providing alternative models and likely projected population needs.

Keywords: *geriatric assessment, long-term care, diagnosis, dependency, public policy, elderly, residential care, nursing home care*

## Introduction

Development and resourcing of services for older people have principally been targeted at maximising independence and avoiding admission to long-term care through active intervention, rehabilitation and care in the community, whilst the development of long-term care has been relatively neglected [1, 2]. The paucity of information regarding present and future long-term care provision undermined the report of the Royal Commission on Long Term Care [3]. Subsequently, limited data on care home residents have emerged from the Health Survey for England 2000, which drew on interviews with over 2,400 people [4]. It reported that, of those aged 65 and over, 4% were resident in care homes: a percentage similar to that in the 1991 Census of England and Wales. Overall, 75% of all residents in care homes were severely disabled and a high hospital utilisation rate by care home residents was noted. Acute hospital usage

in the UK has received increasing scrutiny with most attention having been focused on discharge of 'bed blockers', culminating in policies that penalise authorities who delay discharge [5]. There is increasing awareness of the importance of chronic disease management and alternatives to hospital admission. Chronic disease management for care home residents has been reported to be inferior to that of age-matched community peers [6] and variations in acute service utilisation by care homes [7] provide further evidence that care home residents have unmet and inconsistently addressed healthcare needs. In the USA, a planned approach to the problems of care home residents has proved successful in maintaining health and reducing acute episodes [8]. This experience has prompted a number of pilot projects [9] in the UK.

Nine of the original commissioners from the Royal Commission on Long Term Care issued a statement in September 2003 [10] that included a reaffirmation of the importance of a national care commission, 'a permanent, powerful body' to report on the interrelated facets of care. In the absence of such information the evidential basis for health and care policy remains weak. This paper reports a census of clinical issues and disability characteristics across BUPA's national portfolio of care homes.

## Methods

A census form was developed, piloted, refined (Figure 1) and distributed to the 244 care homes that constitute BUPA's UK portfolio. The census was conducted during the period 30 January to 5 February 2003. Instructions required that a senior member of staff on each unit completed a form for every resident at the time of the census. All forms were read using a Fujitsu 4340C sheet reader and information collated using Kofax Ascent 5.5 software. Whilst each form contained the name of the resident, this was not electronically captured but used to ensure non-duplication of census data. Supplementary data regarding the population was accessed from the company's management information system.

## Results

Two-hundred and forty-four homes yielded 15,483 census returns from a resident population base of 16,043 at the time of the census, a return rate of 97%. The company's management information system typically describes the resident population as being 73.5% female. Regarding age distribution, 8.66% of the population were under 70, 20.68% between 70 and 80, 42.77% aged 80–90 and 25.78% over 90.

Of those surveyed, 96.4% were classified as long-term residents with no plan for discharge, with 3.6% temporary (intermediate care, respite, etc.). Overall (both residential and nursing homes) 24% of residents were ambulant, 32% ambulant with assistance and 44% entirely immobile. Only 22% of residents were said to have a normal mental state, 64% were confused or forgetful, 20% were reported to exhibit challenging behaviour and 19% were described as depressed or agitated. Overall, 27% were confused and immobile and incontinent.

Table 1 breaks these findings down between social residential and nurse-led care. The reasons or principal diagnoses associated with admission to care are tabulated in Table 2.

Censors were asked to record the leading diagnosis/reason for admission for each person. When a combination of factors contributed inextricably they could record all those relevant. Fifty percent of the resident population were reported to have a single known diagnosis/reason, 24% had two and 17% had three or more.

In addition to information on diagnosis we sought information on admissions that were related to non-specific frailty or social factors. Of the 3,799 residents whose admission was attributable to 'frailty' only 964 had no accompanying diagnosis and of the 1,968 residents with housing, family or social issues only 457 did not have a diagnosis. Therefore, only 1,421 residents did not have an identifiable clinical driver for care, under 10% of the population.

## Discussion

The collection and collation of the census data presented here affirm the practicality of data acquisition in the care home population. These findings are likely to be representative of the clinical profile and patterns of dependency in residential and nursing care homes more generally across the UK. BUPA's portfolio of homes has a considerable diversity, ranging from small homes to large facilities of 180 beds. The population studied is 73% state funded and 27% self-funded, figures that are similar to nationally reported rates [11]. Residents are generally referred for care through local health and social services including the majority of self-funders. Self-funding is overwhelmingly a consequence of means testing rather than choice.

The traditional perspective that frail older people's problems are unique combinations of conditions and circumstances is challenged by the finding that over 70% of care home placements are related to dementia, stroke and Parkinson's disease. The census probably under-reports the clinical burden of the resident population, as homes are frequently not fully appraised of a resident's medical status, and residential home care workers rather than health professionals will have completed many census forms in residential settings.

The preponderance of placements determined by clinical and disability factors contrasts with fewer than 10% whose admission was occasioned by housing, family or social needs without a reported 'clinical' driver. Care home commissioning, provision and regulation presently reflects a social model of care both in England and to a lesser extent in Scotland [12]. Whilst we have no ability from our data to understand the impact of social factors on the decision to enter care in people with clinical and disability factors, our findings are supportive of a greater need for health assessment and ongoing support. At the very least, inadequate attention to health needs is likely to undermine social aspects of care and life quality.

The overlapping illness and disability profiles of residents in nurse-led care and social residential settings may represent continued progression expected of chronic disease. However, this raises uncertainty regarding eligibility for, and equity of,

# Resident census form 2003

This census questionnaire is designed to give us a better understanding of the needs of our residents. Please read the notes and examples at the beginning of each section before answering

Resident's first name (please print in BLOCK CAPITALS)

Resident's last name (please print in BLOCK CAPITALS)

## 1. Care type

Please tick one box only

- ☐ Residential
- ☐ Nursing

## 2. Basis of stay

Please tick one box only

- ☐ Temporary (e.g. respite)
- ☐ Permanent

## 3. Care category

Please tick one box only

- ☐ Frail elderly (over 65)
- ☐ Dementia
- ☐ Learning difficulties
- ☐ Mental disorder not including learning difficulties or dementia
- ☐ Young physically disabled
- ☐ Convalescent / intermediate care
- ☐ Terminal care / palliative care

## 4. Functional problems

This question covers four areas that affect the resident's care requirements - mobility, incontinence, sensory impairment and mental state. Please tick the appropriate boxes.

E.g. if a resident was confined to bed, part a) would be filled in as follows:

- ☑ Totally dependent

4a **Mobility (please tick one box only)**

- ☐ Mobile
- ☐ Mobile with assistance
- ☐ Totally dependent

4b **Mental state (please tick all boxes that apply)**

- ☐ Normal
- ☐ Confused or forgetful
- ☐ Challenging behaviour
- ☐ Depressed or agitated

4c **Senses (please tick one box only)**

- ☐ No sensory impairment
- ☐ Moderate hearing and / or sight problems (doesn't affect quality of life)
- ☐ Severe sight impairment (affects quality of life)
- ☐ Severe hearing impairment (difficulty in following what is said, even if a hearing aid is worn)
- ☐ Severe hearing and sight impairments

4d **Continence**

- ☐ Continent
- ☐ Urinary incontinence only
- ☐ Faecal incontinence only
- ☐ Urinary and faecal incontinence

| | Yes | No |
|---|---|---|
| Does resident wear pads? | ☐ | ☐ |
| Does resident have a catheter? | ☐ | ☐ |

BUPA Care Homes

Please turn over

Figure 1. Front and reverse sides of resident census form.

# Resident census (continued)

## 5. Admission reason / diagnosis

Based on the resident's records and/or your knowledge of him/her, tick the box(es) that best describe the medical diagnosis **that led to their admission.**
Do not include any additional conditions if they were not the main reason for admission.

E.g. "Mrs A admitted due to dementia" - Tick the 'Dementia' box only
"Mrs B admitted due to dementia. Also has arthritis in fingers" - Tick the 'Dementia' box only
"Mrs C admitted due to a combination of dementia and severe arthritis" - Tick both the "Dementia" and "Arthritis" boxes
If the original reason for admission is not known, please tick the 'Unknown' box

| **Neurological & Mental Illness** | |
|---|---|
| Stroke | ☐ |
| Dementia including Alzheimer's | ☐ |
| Parkinson's | ☐ |
| Motor Neurone Disease | ☐ |
| Huntington's Disease | ☐ |
| Multiple Sclerosis (MS) | ☐ |
| Cerebral palsy | ☐ |
| Epilepsy | ☐ |
| Neurological Trauma (head/spinal injuries) | ☐ |
| Schizophrenia | ☐ |
| Depression | ☐ |
| Manic Depression | ☐ |
| Learning difficulties | ☐ |

| **Musculo-skeletal** | |
|---|---|
| Arthritis | ☐ |
| Osteoporosis | ☐ |
| Fractures | ☐ |
| Missing limb(s) | ☐ |

| **Cardio-respiratory** | |
|---|---|
| Heart disease | ☐ |
| Lung / chest disease | ☐ |

| **Sensory impairment** | |
|---|---|
| Sight | ☐ |
| Hearing | ☐ |

| **Other medical conditions** | |
|---|---|
| Diabetes & endocrine | ☐ |
| Cancer | ☐ |

| **Miscellaneous** | |
|---|---|
| Frailty (unspecified) | ☐ |
| Housing | ☐ |
| Family / social reasons | ☐ |
| Unknown | ☐ |
| Other (please specify below) | ☐ |

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BUPA Care Homes

Figure 1. Front and reverse sides of resident census form. *continued*

**Table 1.** Aspects of dependency (actual numbers in parentheses)

| | Residential | Nursing | Overall |
|---|---|---|---|
| 1. Mobility | *n* = 3,894 | *n* = 11,335 | *n* = 15,287 |
| Ambulant | 40% (1,566) | 18% (2,059) | 24% (3,642) |
| Ambulant with assistance | 43% (1,687) | 28% (3,228) | 32% (4,933) |
| Entirely dependent | 16% (641) | 53% (6,048) | 44% (6,712) |
| 2. Mental State | *n* = 3,849 | *n* = 11,104 | *n* = 15,015 |
| Normal | 31% (1,175) | 19% (2,110) | 22% (3,295) |
| Confused or forgetful | 60% (2,319) | 65% (7,231) | 64% (9,591) |
| Challenging behaviour | 11% (423) | 23% (2,549) | 20% (2,989) |
| Depressed or agitated | 12% (479) | 21% (2,352) | 19% (2,840) |
| 3. Continence | *n* = 3,832 | *n* = 11,278 | *N* = 15,166 |
| Continent | 53% (2,044) | 20% (2,253) | 28% (4,311) |
| Urinary incontinence only | 24% (930) | 19% (2,151) | 20% (3,089) |
| Faecal incontinence only | 1% (45) | 1% (95) | 1% (141) |
| Urinary and faecal incontinence | 21% (813) | 60% (6,779) | 50% (7,625) |

Data from a small number of partially completed census returns have been included in the results presented in Tables 1 and 2. This means that the overall figure is not always equal to the sum of the corresponding residential and nursing figures.

**Table 2.** Admission reasons/diagnosis (actual numbers in parentheses)

| | Nursing | Residential | All residents |
|---|---|---|---|
| Dementia | 38% (4,272) | 31% (1,164) | 36% (5,456) |
| Frailty | 22% (2,499) | 34% (1,282) | 25% (3,799) |
| Stroke | 25% (2,827) | 12% (453) | 22% (3,287) |
| Sight impairment | 12% (1,349) | 16% (600) | 13% (1,958) |
| Arthritis | 12% (1,392) | 15% (560) | 13% (1,957) |
| Family/social reasons | 9% (968) | 20% (773) | 12% (1,748) |
| Heart | 10% (1,160) | 10% (382) | 10% (1,547) |
| Diabetes | 9% (993) | 7% (284) | 8% (1,280) |
| Hearing impairment | 6% (695) | 9% (328) | 7% (1,025) |
| Depression | 6% (673) | 8% (319) | 7% (998) |
| Other | 7% (766) | 6% (222) | 7% (992) |
| Fractures | 7% (777) | 4% (167) | 6% (951) |
| Parkinsonism | 5% (613) | 5% (187) | 5% (807) |
| Lung or chest disease | 5% (519) | 4% (144) | 4% (664) |
| Cancer | 5% (508) | 4% (139) | 4% (651) |
| Osteoporosis | 4% (459) | 4% (142) | 4% (604) |
| Epilepsy | 4% (400) | 2% (81) | 3% (481) |
| Unknown | 2% (177) | 6% (214) | 3% (392) |
| Neurological trauma | 2% (201) | 1% (26) | 2% (229) |
| MS | 2% (207) | 1% (19) | 1% (226) |
| Learning difficulties | 1% (167) | 1% (54) | 1% (221) |
| Housing | 1% (130) | 2% (90) | 1% (220) |
| Schizophrenia | 1% (167) | 1% (40) | 1% (208) |
| Missing limb | 1% (165) | 1% (43) | 1% (208) |
| Manic depression | 1% (81) | 1% (38) | 1% (119) |
| Motor neurone | 0% (50) | 0% (3) | 0% (53) |
| Huntington's | 0% (45) | 0% (7) | 0% (52) |
| Cerebral palsy | 0% (38) | 0% (9) | 0% (47) |

NHS care. The health service commissioner has reported inadequacies of eligibility assessment for fully funded NHS care [13]. Furthermore, new policies intended to ensure that local authorities offer prompt discharge options of ongoing care following the acute phase of a medical admission have been criticised as failing to address the needs of the 'frail elderly and people with long-term illness' [14]. We suggest that the health/social interface and desire to provide patient-centred care may be more easily managed through the adoption of diagnosis as a starting point for health and care management. Patient-centred choice within the context of the opportunities (treatment and rehabilitation) and limitations (prognosis and disability) could be enabled by this approach. The prominence of relatively few diagnoses in the majority of residents should make this feasible.

A large proportion of the care home residents surveyed have diseases or disabilities, particularly loss of mental capacity and continence, that make independent living in the community with intermittent care support an impractical or prohibitively expensive option. This perspective needs consideration in the context of population trends and the aspiration to reduce care home usage through preventative strategies and various forms of community care. Improvements in older people's ability to carry out the activities of daily living are forecast [15], but within this positive picture a predictable subset of older people will have complex needs. Loss of mental capacity, predominantly as a consequence of dementia or stroke, remains the single biggest issue. It has been predicted [16] that the number of people with cognitive impairment in institutions will rise by 63% between 1998 and 2031 based on present service usage.

For personal choice care commissioning needs to anticipate changing needs to avoid unnecessary acute episodes and deterioration. Commissioners also need to consider the impact of the loss of 60,000 care home beds in the UK over the past 5 years [17] which may threaten the care of older people and the capability of the acute hospital service [1].

The importance of clinical factors in institutional care questions the appropriateness of present and planned regulatory approaches for care homes. Care regulation is the responsibility of the National Care Standards Commission (NCSC), to be succeeded from April 2004 by the Commission for Social Care Inspection (CSCI). The new CSCI is described as a single comprehensive inspectorate for social care, encompassing all of the work of the Social Services Inspectorate (SSI), the joint review team of the SSI/Audit Commission, and the functions of the existing NCSC. Neither the NCSC nor the CSCI has significant health resource or responsibility. Healthcare regulation presently operates through the Commission for Health Improvement (CHI), to be succeeded by the Commission for Health Audit and Inspection (CHAI) in April 2004. The CHI and CHAI have a remit for health services including the assessment of older people for the Registered Nurse Care Contribution as well as eligibility for fully funded NHS care as already scrutinised by the health service commissioner [13]. Further development will be necessary to ensure that patient-centred care does not fall between regulatory stools.

Without the context of the health profile, disability and prognostic status of individuals, monitoring of individual residents' progress (outcomes) and understanding the performance of health and care services is unlikely to be adequate. The development of a single assessment process from

conceptual model to a mandatory instrument of measurement spanning health and care could, with electronic capture of data [18], provide information in a more sophisticated manner to the census data presented on an ongoing basis.

## Keypoints

- Disease and disability, rather than social factors, lead to long-term institutional care.
- Dementia, stroke and other neurodegenerative disease with mental impairment dominate.
- It is unlikely that the needs of people with the levels of dependency found in this study can practically be met in the community.
- There is an overlap between care needs in residential and nursing care settings.
- Assessment and regulatory systems are poorly matched to the needs of people in care.

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## Conflicts of interest declaration

The authors are all employed by BUPA but have no conflicting interests in the preparation and reporting of this paper.

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