

Independent Review of NHS Continuing Healthcare

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1. FOREWORD

Dear Cabinet Secretary

We have pleasure in submitting the report of the Independent Panel on NHS Continuing Healthcare (NHS CHC).

Throughout the months of our inquiry and in the preparation of this report we have been privileged to have received information, advice and comment from a wide range of individuals who have given generously of their time and expertise. We owe them individually and collectively a great debt of gratitude.

Scotland is blessed with an impressive number of dedicated and highly skilled professionals in health and social care, in Local Authorities, and in private and voluntary organisations. They share a common aim to provide the best possible care to those in need and in their charge.

We do not claim to have solved every challenge which we identified in the course of our study but we do hope that our work and recommendations will make a contribution to an equitable, compassionate, accessible and sustainable system to go forwards to meet both the current and future needs of the people of Scotland.

We are very aware of the particular challenges faced by those individuals under the age of 65 who fall outwith the eligibility of free personal and nursing care. We are pleased that you brought this to public attention in the media in December 2013. We consider that although outwith our remit that further work in that area requires to be done.

We commend our report and its recommendations for your consideration.

Yours sincerely

The Panel

2. EXECUTIVE SUMMARY

- 2.1 In June 2013, in response to concerns raised in the media regarding the application of the guidance contained within CEL 6 (2008) by Health Boards in Scotland, the Cabinet Secretary for Health and Wellbeing commissioned an independent panel to review the delivery, monitoring and governance of NHS Continuing Healthcare (NHS CHC) in Scotland.
- 2.2 NHS CHC is a package of care provided and solely funded by the NHS, operated under the guidance contained in the Scottish Government's CEL 6 (2008).
- 2.3 The NHS pays the total cost of NHS CHC and not the Local Authority nor the individual. This may be for a prolonged period of time but is not necessarily for life and is subject to regular review.
- 2.4 Importantly and in contrast to other types of care package, accommodation costs are fully funded by the NHS, irrespective of the ability of the individual to contribute to these costs.
- 2.5 NHS CHC is not available to individuals living in their own homes.
- 2.6 NHS CHC is available to individuals of all ages with any illness or disability provided they meet the eligibility criteria described in CEL 6 (2008).
- 2.7 In 2013, 1,711 individuals were receiving NHS CHC; three quarters of whom were in NHS facilities, the remainder in private nursing homes. These 1,711 individuals represent approximately 5% of all those in institutional care in Scotland in 2013.
- 2.8 Approximately 33,000 individuals in institutional care are not in receipt of NHS CHC. They are predominantly cared for in private or Local Authority care homes and are eligible for assessment for free personal and nursing care irrespective of their ability to contribute to these costs but liable to charging for their accommodation costs dependent on their personal financial circumstances.
- 2.9 The Independent Panel received verbal and written feedback and submissions from all 14 Health Boards in Scotland, representatives of Local Authorities, and a variety of voluntary organisations, and reviewed data compiled by ISD Scotland from the annual census of NHS CHC.

2.10 The Panel concludes that:

2.10.1 CEL 6 (2008) is no longer an appropriate instrument to operate NHS CHC. Specifically:

- The eligibility criteria are open to individual clinical interpretation. Consequently, although eligibility for NHS CHC remains a clinical decision, it is subjective, varying between clinicians in the same and different Health Boards and contributing to a variation of provision.
- It has not resulted in a consistent level of provision and availability of either NHS facilities or alternative Local Authority, private or third sector facilities amongst Health Boards across Scotland.
- It fails to recognise the needs of a wide range of differing patient and client groups.

- 2.10.2 Many professionals and most of the public have limited or no awareness of NHS CHC. This further contributes to variability in provision and also means that not all of those considered for NHS CHC receive an adequate explanation of the process or the appeals procedures.
- 2.10.3 The appeals procedures are “in house” within Health Boards, and there is neither externality nor independent advocacy other than referral to the NHS complaints procedures or finally to the Scottish Public Services Ombudsman (SPSO).
- 2.10.4 The annual census process is not fit for purpose in its current form. The data lacks reliability and credibility and cannot safely be used to make meaningful comparisons of NHS CHC provision among Health Boards nor over periods of time. Specifically:
- The census describes the number of individuals in receipt of NHS CHC on one day of each year, and not the total number of individuals in receipt of NHS CHC over a whole year.
 - Methods of data collection vary substantially among Health Boards.
 - Health Board level scrutiny of data is extremely variable.
 - The data is not subject to external audit or scrutiny.
 - NHS Scotland has not used the data to support the provision of care in non-NHS settings across Scotland.

2.11 The Panel recommends that:

- 2.11.1 CEL 6 (2008) should be completely revised and the term NHS CHC should be replaced with the term “Hospital Based Complex Clinical Care” (HBCCC). The choice of this term emphasises the recommendation that HBCCC should be a form of care that is only provided in facilities wholly funded and managed by the NHS.

This revision should adhere to the following principles:

- 2.11.2 Eligibility for HBCCC should continue to be decided by specialist clinicians in partnership with a professional multidisciplinary team. No specific list of eligibility criteria, or scoring system, based on a description of an individual’s current or predicted future condition, prognosis or care needs, should form part of the guidance. For the future the primary eligibility question should simply be **“Can this individual’s care needs be properly met in any setting other than a hospital?”**
- 2.11.3 The current annual census should be replaced. Consequently, all individuals in NHS hospital care at a point three months after admission should be considered for HBCCC unless they are a delayed discharge. At this point and every three months thereafter as necessary, a clinician and another member of the multidisciplinary team responsible for the care of the individual should assess and affirm this need on specifically designed documentation.
- 2.11.4 Health Boards and Local Authorities should determine the number of HBCCC beds that will require to be provided in their area. The Scottish Government should monitor progress towards more equitable provision than currently exists.

- 2.11.5 The Scottish Government should, via the new census recommended in this report, monitor the shift of long term care venues from NHS to more homely care settings in all Health Boards.
- 2.11.6 An easy to read document containing information on HBCCC should be made widely available to patients, carers and all health care professionals. The document should be reviewed at a minimum every three years and revised at that time if thought necessary. The document should be available in printed form, in appropriate languages and formats.
- 2.11.7 When there is a dispute between an individual, their family and a multidisciplinary team about the most appropriate venue of care the decision should continue to be reviewed on an internal basis by a clinician from the same Health Board.
- 2.11.8 The principles and recommendations outlined in this report should apply equally to individuals of all ages.
- 2.11.9 It would be unfair and unjust if those who are currently in receipt of NHS CHC are disadvantaged by the proposals and the current financial arrangements should remain for these individuals without detriment.

3. BACKGROUND

3.1 Context of the Review

3.1.1 Mr Alex Neil, The Cabinet Secretary for Health and Wellbeing was approached by the media in June 2013 to respond to a claim that relatively fewer people were receiving NHS Continuing Healthcare (NHS CHC) in Scotland than in England. The annual NHS CHC census was published some two weeks after the initial media interest and showed a 15% reduction in the numbers of individuals receiving NHS CHC in Scotland since March 2012. The census also showed a wide variation of provision among individual Health Boards.

3.1.2 NHS CHC is described in national guidance dated February 2008 - CEL 6 (2008)¹:

8. NHS continuing healthcare is a package of continuing health care provided and solely funded by the NHS. The NHS, and not the local authority or individual, pays the total cost of that care. NHS continuing health care may be for prolonged periods but not necessarily for life and entitlement should be the subject of regular review.

3.1.3 The purpose of the guidance in CEL 6 (2008) was to:

- Promote a consistent basis for the assessment of, and provision of, NHS continuing health care.
- Ensure care provision is based on robust assessment and decision making processes.
- Ensure that patients and their carers have access to relevant and understandable information.
- Agree a basis for the development of effective local agreements on inter agency and multi disciplinary working in relation to NHS continuing health care.

3.1.4 It was hoped that CEL 6 (2008) would counter early criticism of the guidance in MEL (1996) 22², which included:

- People unaware of NHS CHC - when asked, some professionals did not know about it or said it “only applied in England”
- Decisions not consistent or transparent
- Decision Support Tool needed
- Decisions are financially driven or influenced
- People unaware of right for second opinion

3.1.5 Following the introduction of CEL 6 (2008), a bi-annual Balance of Care / Continuing Care Census³ was introduced to collate information on all individuals receiving NHS

¹ http://www.sehd.scot.nhs.uk/mels/CEL2008_06.pdf

² http://www.sehd.scot.nhs.uk/mels/1996_22.pdf

CHC across Scotland. It was intended that information derived would not only monitor the numbers of those requiring NHS CHC but also inform the Shifting the Balance of Care⁴ policy agenda. In 2011 the census became annual.

- 3.1.6 In March 2013, the census recorded that 1,711 “Category A” individuals were receiving NHS CHC across Scotland, a decrease of 15% from the March 2012 census. 76% of NHS CHC individuals were in a hospital and 23% of individuals were in care homes. Almost all of those in care homes were in two of the fourteen Health Board areas.
- 3.1.7 A further 562 “Category B” individuals were identified in the census. These individuals did not meet the criteria for NHS CHC but had been in hospital for more than one year and had no planned date of discharge.
- 3.1.8 The 1,711 “Category A” individuals represented approximately 5% of all those in institutional care in Scotland in 2013.
- 3.1.9 The remaining 33,000 individuals in institutional care were not in receipt of NHS CHC. They were predominantly cared for in private or Local Authority care homes and were eligible for assessment for free personal and nursing care⁵ irrespective of their ability to contribute to these costs but liable to charging for their accommodation costs if their personal finances permitted.
- 3.1.10 In July 2013 the Cabinet Secretary for Health and Wellbeing requested that an Independent Review Panel be set up to:
 - i. assess whether guidance was being followed, and a consistent approach was being taken across Scotland
 - ii. confirm whether record keeping was adequate, and decisions made were being clearly and appropriately articulated to all concerned
 - iii. assess whether improvements were needed to raise awareness of NHS CHC amongst professionals and the general public
 - iv. assess whether the decision making process was based on clinical need rather than financial circumstances
 - v. consider whether an independent appeals process was required

3.2 Strategic and Policy Background

- 3.2.1 All Health Boards in Scotland, in partnership with Local Authorities and the private and third sector, and as part of the Shifting the Balance of Care and other policies, aim to enable as many people as possible to stay in their own homes for as long as possible, and, when living at home is no longer possible to provide care in a homely setting in the community rather than in an NHS hospital ward.
- 3.2.2 In recent years the capacity of the care system to manage individuals’ care needs in domiciliary settings and care homes has increased markedly and the absolute requirement to manage individuals in NHS hospital facilities has consequently declined. Individuals for whom there was no option but to remain in hospital care ten

³ <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2013-06-25/2013-06-25-CC Census-Report.pdf>

⁴ <http://www.shiftingthebalance.scot.nhs.uk/improvement-framework/>

⁵ <http://www.scotland.gov.uk/resource/doc/55971/0015597.pdf>

years ago can now be safely and effectively managed outwith an inpatient hospital setting.

- 3.2.3 All Health Boards and Local Authorities recognise the need to provide support, treatment, care and time to individuals who, typically after a period of acute illness or hospitalisation, wish to return home but are, in the first instance, unable to do so.
- 3.2.4 A variety of services, frequently referred to as Intermediate Care Services⁶, have developed to maximise the potential of individuals to return to and remain in their own homes. These services, which may be domiciliary or non-domiciliary, have developed at different rates in different parts of Scotland. Non-domiciliary services are provided and funded in both NHS and non-NHS facilities.
- 3.2.5 All Health Boards and Local Authorities recognise that, even with further rehabilitation or reablement, some individuals do not improve sufficiently to return to their own homes or to alternative domiciliary settings such as sheltered housing. The care needs of these individuals are then met in non-domiciliary settings, provided by the NHS, Local Authority, the private and third sector (residential, nursing or care homes).
- 3.2.6 Currently, there is substantial variation in the capacity in each of these sectors in different Health Boards areas. Some Health Boards have a relatively large number of private sector homes available to provide for individuals who cannot return home. Others have relatively few and two island areas have none. Some Health Boards have retained significant numbers of NHS CHC hospital beds whereas others have retained none.
- 3.2.7 NHS CHC is typically provided in NHS facilities but CEL 6 (2008) does allow provision of such care in care homes. In the most recent census, 23% of individuals in receipt of NHS CHC in Scotland were in private care homes, with the vast majority of these in only two of the fourteen Health Board areas. One Health Board provided 50% of its NHS CHC in the private sector, but most had less than 5% of patients receiving NHS CHC in private care homes and six Health Boards did not utilise private care homes for NHS CHC.
- 3.2.8 Individuals judged ineligible for NHS CHC constitute around 95% of all those in non-domiciliary care and are typically care for in private, third sector or Local Authority residential or nursing homes and are liable to Local Authority charging for accommodation costs. All individuals over 65 in such care are eligible for free personal and nursing care. All other aspects of medical care are provided without charge by NHS Primary Care.
- 3.2.9 The use of private care homes for patients who are in receipt of NHS CHC means that an individual care home can have two distinctly funded groups of patients under their care – a very small number of those receiving NHS CHC and the vast majority who are not.
- 3.2.10 While it is the case that continuing health care provided by the NHS in whatever setting is free at the point of delivery, it is also the case that, depending on individual circumstances, continuing entitlement to a range of welfare benefits is affected by extended stay in hospital.

⁶ <http://www.scotland.gov.uk/Resource/0039/00396826.pdf>

3.3 The Review Process

- 3.3.1 After an initial meeting and briefing from the Health Department, the Panel operated entirely independently of Scottish Government.
- 3.3.2 The Panel met representatives from all 14 territorial Health Boards in Scotland. The very open discussions that occurred centred on a series of questions relating to:
- Eligibility
 - Decision making
 - Record keeping
 - Appeals
 - Communications and awareness
 - Transparency
- 3.3.3 It was agreed at every review meeting that any comments made would not be attributable to any individual or any individual Health Board in the report in order to encourage open debate and discussion.
- 3.3.4 The Panel did not stipulate that Health Boards include representation from any particular group of clinicians. However, those Health Boards that did provide clinical representation tended to provide individuals from secondary care.
- 3.3.5 The Panel did not discuss the specific circumstances of any individual who had appealed their eligibility for NHS CHC.
- 3.3.6 The Panel liaised with the Convention of Scottish Local Authorities (COSLA) during the duration of the review and met with representatives from the Association of Directors of Social Work.
- 3.3.7 The Panel wrote to 15 Voluntary Organisations inviting their feedback on awareness and eligibility, and seven responses were received. In addition to this, a meeting was held with one of the organisations to gain further feedback.
- 3.3.8 The evidence gathered from Health Boards, Local Authorities and Voluntary Organisations has been used to form the basis of the report and recommendations.

4. FINDINGS

4.1 CEL 6 (2008) and Assessment of Eligibility for NHS CHC

- 4.1.1 CEL 6 (2008) was introduced to bring clarity to the process of NHS CHC following MEL (1996) 22. The sections relating to eligibility criteria are detailed below:

44. Continuing inpatient care should be provided where there is a need for ongoing and regular specialist clinical supervision of the patient as a result of-

- (a) the complexity, nature or intensity of the patient's health needs, being the patient's medical, nursing and other clinical needs overall;
- (b) the need for frequent, not easily predictable, clinical interventions;
- (c) the need for routine use of specialist health care equipment or treatments which require the supervision of specialist NHS staff; or
- (d) a rapidly degenerating or unstable condition requiring specialist medical or nursing supervision.

- 4.1.2 Twelve of the fourteen Health Boards were concerned with the application of CEL 6 (2008). Changes in care have overtaken CEL 6 (2008) and it did not now adequately take into account changes in demography, advances in clinical and community care, advances in technology, expectations of individuals and families, nor advances in the role and training of other professional members in community based multidisciplinary teams.
- 4.1.3 The clinical interpretation of the wording of CEL 6 (2008) varied significantly, particularly in relation to the words "regular", "specialist", "complexity", "intensity", "frequent" and "rapidly".
- 4.1.4 There were inconsistencies in the application of CEL 6 (2008) among Health Boards in part relating to variable clinical interpretation of the criteria, in part to the relative availability of different care facilities and in part to differing strategic approaches to a reduction in NHS long-term bed provision.
- 4.1.5 Some Health Boards have actively pursued a policy of providing NHS CHC in private care homes, others have not. Some designated a specific number of their beds as NHS CHC beds while others did not designate any for this purpose.
- 4.1.6 Some Health Boards recorded no individuals as meeting the NHS CHC eligibility criteria but clearly described individuals receiving care in NHS facilities (typically cottage or community hospitals) that was, in some cases, for life.
- 4.1.7 These same individuals, had they been resident in another Health Board area, would have received their care in a private care home where they may have been subject to charging policies.
- 4.1.8 Notwithstanding the impact of an ageing population, most Health Boards believed that a reduction in provision of NHS CHC was to be expected as part of the Shifting the Balance of Care agenda.
- 4.1.9 A small minority of Health Boards used a decision making tool. Such a tool was suggested in CEL 6 (2008) but never produced.

- 4.1.10 Most Health Boards were aware of the need to undertake a regular review of individuals in receipt of NHS CHC to establish whether they still fulfilled the eligibility criteria, although none could provide detailed audit data relating to such a process and only a minority were able to indicate how many individuals had been found to be ineligible after such an assessment.
- 4.1.11 All Health Boards and Local Authorities acknowledged that some individuals were admitted to care homes direct from their own homes. However, the Panel could not identify any systematic screening process with the specific purpose of identifying eligibility for NHS CHC.
- 4.1.12 All Health Boards regarded the assessment of NHS CHC eligibility for individuals in NHS inpatient care as their responsibility. However, it was unclear whether they regarded the assessment of individuals in other settings, particularly those living in a care home, as their own responsibility or that of the Local Authority.
- 4.1.13 It was clear that people living in care homes had their care needs reviewed at intervals. However, it was not clear that in reviewing the care needs of those in care homes, that there was systematic consideration of whether an individual's needs had changed to such an extent that they would now meet the criteria for NHS CHC.
- 4.1.14 Many Health Boards emphasised that if an individual's care needs could not be met in a care home setting, then the patient would be admitted to hospital. At that point their need for NHS CHC would be assessed.

4.2 Decision Making and Accountability

- 4.2.1 The process relating to decision making outlined in CEL 6 (2008), as below, contains information relating to WHO makes the decision, WHERE the decision is made, WHY the decision is made and WHEN the decision is made.

43. The consultant (or GP in some community hospitals) will decide, in consultation with the multi-disciplinary team, whether the patient-

- (a) needs inpatient care arranged and funded by the NHS;
- (b) needs a period of rehabilitation or recovery, arranged and funded by the NHS; or
- (c) should be discharged from inpatient care

- 4.2.2 Decision making in most Health Boards typically fell to an individual Consultant as the final decision maker with some expressing concern of feeling isolated by the process.
- 4.2.3 There appeared to be no routine involvement of primary care clinicians in the decision making process, although some could be involved if they had responsibilities in cottage or community hospitals operated by the NHS.
- 4.2.4 Clinicians were aware of the financial implications for individuals and their families of the decision regarding eligibility but were not influenced by such implications in their decision making.
- 4.2.5 Eligibility frequently appeared to be based on a clinical assessment of whether an individual's care needs could be met in a non-NHS setting, typically a private care home, rather than a direct assessment against the CEL 6 (2008) criteria.
- 4.2.6 As a result, given the variation in provision of non-NHS care, individuals who could have been managed in a private care home in one Health Board area could be managed in an NHS facility in another.
- 4.2.7 Some clinicians stressed that assessment of care needs could not be restricted to "a moment in time" but was an ongoing process. Some patients moved in and out of the eligibility criteria over time. It was also felt that overly rapid determination of a patient's status in regard to eligibility for NHS CHC could lead to inappropriate decisions being made about their future care.
- 4.2.8 Assessment of eligibility was also in part related to perceived life expectancy. Some clinicians felt that it was inappropriate to place an individual with a terminal diagnosis and a rapidly deteriorating condition, but who did not meet the current CEL 6 (2008) eligibility criteria, in a private care home unless it was certain that local community care provision was such that the individual would not require to be re-hospitalised as their condition deteriorated.
- 4.2.9 Furthermore, the question of defining an individual as in receipt of NHS CHC usually only arose when a move from one care setting to another was being considered. Consequently, terminal patients with high level and escalating care needs who were judged too frail to be moved, and were subsequently cared for in NHS wards until they died, would not always be documented as being in receipt of NHS CHC even though they met the eligibility criteria.

- 4.2.10 Managers all agreed that NHS CHC was a clinical decision, made without budgetary constraints.
- 4.2.11 Few Health Boards were able to provide precise financial information relating to their recent, current or projected budgets with regard to NHS CHC.
- 4.2.12 The Panel were concerned that there was very little evidence of over-arching co-ordination of strategic thinking about or operational accountability for NHS CHC by management in the majority of Health Boards.
- 4.2.13 Some Local Authorities expressed concern that they were not always fully involved in discussions about provision of care following discharge from hospital, be that in a domiciliary or non-domiciliary location, and that the final decision about the location of care should not be the sole responsibility of a secondary care clinician.
- 4.2.14 In some instances, Local Authorities expressed their concerns at being asked to provide increased levels of sophistication in medical care and supervision without the necessary training or support.
- 4.2.15 Progress towards the integration of health and social care appeared variable. Although working relationships generally appeared to be good, there was evidence of some tension between some Health Boards and Local Authorities in agreeing relative financial contributions to community care programmes.
- 4.2.16 Most Health Boards did describe a process of “resource transfer” from Health Boards to Local Authorities.
- 4.2.17 Such resources had been derived predominantly from the closure of NHS facilities, typically “residential” or “long stay” facilities and including facilities previously utilised for NHS CHC. The purpose of this transfer of resource, which had operated for many years in some areas, was to enhance services in the community in a manner that enabled more individuals who had historically required long term care in hospital to be managed in a more appropriate setting.
- 4.2.18 It was unclear whether the “money had followed the patient” in all instances of such resource transfer.

4.3 Documentation, Audit and the Annual Census

Documentation of Decision Making

4.3.1 The requirements for record keeping are set out in CEL 6 (2008) as outlined below:

65. All stages of decision making in relation to the determination of eligibility for NHS continuing health care, including the assessment eligibility decision, care planning and information on the subsequent provision and monitoring of that care should be appropriately and fully documented. Decision makers should be identified and the reasoning behind the decisions clearly explained.

66. It should also be recorded whether or not the individual was satisfied with the decision and what information they were given, including information on the appeals process.

67. Such records, including where eligibility for NHS continuing health care has not been agreed, should be retained for a minimum of six years. In cases involving mental health issues, the records should be kept for the lifetime of the patient. All relevant agencies and care providers will be responsible for maintaining the relevant records.

68. It is expected that any part of the decision making process would be recorded in

- The patient's clinical records
- The Single Shared Assessment
- In the formal record of the multi disciplinary team.

4.3.2 The majority of Health Boards indicated that individuals who were deemed to be eligible for NHS CHC would have this decision recorded in their case notes, typically in the record of a multidisciplinary team meeting.

4.3.3 A small minority of Health Boards used specific additional documentation to record decisions and those that did only used such documentation to indicate eligibility for NHS CHC rather than ineligibility.

4.3.4 No Health Board routinely, systematically or specifically recorded the decision that an individual was ineligible for NHS CHC at routine multidisciplinary team meetings during their stay in hospital or at the point of discharge from NHS care. This was largely due to the fact that it would be a major logistical undertaking that was felt to be excessively bureaucratic.

4.3.5 Given the above, audit of the decision making process for most Health Boards could only be undertaken via a process of retrospective and detailed case note review. As a consequence, most Health Boards were unable to provide figures relating to the total numbers of individuals assessed for NHS CHC, or those judged to be ineligible after such assessment.

4.3.6 Health Boards believed that, in cases in which eligibility for NHS CHC had been questioned, typically by relatives of an individual, there would be specific documentation in the case record that indicated that the individual was judged to be ineligible, following a multidisciplinary team meeting.

- 4.3.7 For the majority of Health Boards, the only information relating to NHS CHC provision and decision making available to the Panel was that published in the annual census and also that provided from appeals and complaints about decisions.

The Annual Census

- 4.3.8 The Scottish Government undertakes an annual census of NHS CHC in accordance with a document issued in September 2009 by Information Services Division (ISD) of NHS National Services Scotland (NSS) entitled “Balance of Care/Continuing Care Census - Definitions and data recording manual⁷”.
- 4.3.9 The census categorises individuals into two categories – “Category A”: in receipt of NHS CHC and “Category B”: in hospital for over one year, but not in receipt of NHS CHC.
- 4.3.10 Although detailed and comprehensive, the guidance for the annual census has not resulted in the provision of reliable, accurate or meaningful information.
- 4.3.11 The principal weakness of the annual census is that a one-off count on a single day in a year does not reflect the total number of people in receipt of NHS CHC during the whole year. Some Health Boards suggested that the length of stay of individuals in NHS CHC had declined over recent years, although data to support this is of variable quality, but if this is the case comparisons of provision over time based on the current “snapshot” methodology will be misleading.
- 4.3.12 Furthermore, most Health Boards could not explain how they made the distinction between “Category A” and “Category B” individuals, with the result that classification is unlikely to be consistent across Health Boards. Most Health Boards were unclear of the specific reasons that might lead to a patient in their care being in “Category B” (not meeting NHS CHC criteria but in hospital for over one year with no definite discharge date set).
- 4.3.13 During the review meetings, most Health Boards demonstrated a low level of corporate awareness of the purpose or methodology of the annual census, with some noting difficulty in collecting census data. Consequently, ownership of the information and accountability for its accuracy was generally extremely low.
- 4.3.14 Some Health Boards based their census return on a count of beds designated as NHS CHC beds, but acknowledged that some individuals in these beds could actually be aiming to return home or be undergoing assessment or awaiting care home placement and not actually meet the CEL 6 (2008) criteria.
- 4.3.15 Some Health Boards had no beds designated as NHS CHC beds, but acknowledged that individuals in some of their facilities, typically cottage or community hospitals, would never return home, and could meet the eligibility criteria for NHS CHC, but were not recorded as such.
- 4.3.16 Some Health Boards based their census returns on a count of specific individuals that were thought or known at that time to be classified as NHS CHC. One Health

⁷ <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/NHS-Continuing-Care/NHS-Continuing-Care-Census-Guidance-updated-February-2013.pdf>

Board reported that all wards recorded NHS CHC individuals on the census day and the collated snapshot figures were then submitted to ISD.

- 4.3.17 Out of area placements were included within the returns for some, but not all, Health Boards.
- 4.3.18 Some Health Boards were uncertain if individuals with learning disabilities were included in their returns.
- 4.3.19 One Health Board reported that, on census day, mental health inpatients with no plan for discharge were counted as “Category A”, rather than “Category B” patients.
- 4.3.20 Most Health Boards were unaware if individuals in hospice facilities were included in their census returns.
- 4.3.21 Only a small minority of Health Boards referred to any continuously collated or systematically reviewed source of internal data to inform or verify their census return.
- 4.3.22 Most Health Boards felt that the census figures were likely to under represent the numbers of individuals actually in receipt of NHS CHC.

4.4 Communication, Awareness and Transparency

- 4.4.1 Patient information guidance in CEL 6 (2008) places responsibility on Health Boards as detailed below:

73. It is important that information on assessment, eligibility, decision making processes and appeals should be made available to patients and their carers, who should be actively involved in any decisions. To this end Health Boards should ensure that the eligibility and the assessment process are clearly explained to both the patient and the carer at an early stage. This information should be in an easy to understand format, be written from a patient's perspective and be available in any form that might be needed – Braille, audio, different languages etc – and be provided in a timely manner.

- 4.4.2 The guidance also states that Health Boards fully explain and document all decisions and provide copies of assessments to individuals and their carers, as well as produce an information leaflet on NHS CHC.

During the course of the review, the Panel found that:

- 4.4.3 NHS CHC did not appear to have been a high profile, high priority or problematic issue to most Health Boards until the media interest and publicity in June 2013.
- 4.4.4 There was broad acceptance from Health Boards, Local Authorities and Voluntary Organisations that most members of the general public have little or no awareness or understanding of NHS CHC.
- 4.4.5 The majority of Health Boards expressed the view that the language of CEL 6 (2008) was unhelpful, unclear and outdated.
- 4.4.6 The publicity which preceded the review had both heightened public awareness and further highlighted the deficiencies in the current guidance.
- 4.4.7 Local Authorities noted that the public perception of free personal and nursing care was that all elements of care were now free and that there was limited understanding of the issues of accommodation costs for many care home residents or of the financial issues relating to the personal and nursing care provision for those under 65.
- 4.4.8 The charging arrangements for care home residents involve a complex calculation that takes into account entitlement to free personal and nursing care, pensions and other benefits, savings and capital assets. Access to NHS CHC does impact on entitlements to benefits. However, savings and capital assets are not used to pay for accommodation costs as they would be for other care home residents.
- 4.4.9 There was a general acknowledgement that many professionals working in the wider health and social care system did not have sufficient knowledge of NHS CHC.
- 4.4.10 Health Boards had made significant efforts to raise the awareness of staff in the period following the implementation of CEL 6 (2008) but few had any systematic method of ensuring that awareness was maintained.

- 4.4.11 There was a consistent view from Health Boards that GPs and other primary care professionals had little awareness of NHS CHC.
- 4.4.12 There was also a view that NHS CHC had not been considered a key strategic issue in recent years.
- 4.4.13 Most Health Boards used the centrally produced NHS Scotland information leaflet to communicate information regarding NHS CHC to individuals and their carers. A small minority had developed bespoke local versions.
- 4.4.14 Most Health Boards only provided written information regarding NHS CHC to those who requested it or those who challenged or appealed against a decision not to provide NHS CHC. There was virtually no information freely and openly available in written or electronic form for individuals and carers to read and fully consider. Even where there was such information, there was no strategy to ensure that it was freely available in wards or relevant clinical areas.
- 4.4.15 The response provided by Voluntary Sector organisations reflected a very similar position to that of Health Boards and Local Authorities in terms of awareness. Whilst there is a small group of well informed staff whose work requires them to have a detailed knowledge of NHS CHC, there is a much larger group of staff, users and carers who have little or no knowledge or understanding.
- 4.4.16 The Panel noted in particular comments from two Voluntary Organisations:

“For us the issue is not the level of awareness that we have of these systems, rather there is a more general lack of awareness of NHS Continuing Care amongst health and care professionals, and in the general public.”

“[We are] well aware of the availability of and eligibility for NHS Continuing Healthcare. We are also aware that families of people who have had a stroke are often not offered the necessary information to apply for NHS CHC, or only given the information if they ask for it. We also know that NHS staff do not always have a sufficient level of understanding of the availability of NHS Continuing Care”

4.5 Appeals

4.5.1 Guidance on the appeals process is outlined in CEL 6 (2008) as below:

122. Where an individual does not agree with the decision on eligibility for NHS continuing health care, or decision to discharge, he or she (or carer or advocate) can appeal the decision by requesting a second opinion from another appropriate, competent medical professional.

- 4.5.2 Most decisions regarding the appropriate venue of care for individuals who could not live at home are reached quickly, smoothly and effectively in a partnership between the individual, their carer, and a multidisciplinary team.
- 4.5.3 A small proportion of individuals and carers dispute decisions regarding the venue and funding of care recommended by a multidisciplinary team. Typically this relates to the decision that an individual does not require to stay in hospital.
- 4.5.4 It was a widely held view that disputes are more likely to relate to the financing of care in a non-NHS setting, rather than the quality of care.
- 4.5.5 The number of appeals had historically been low but had risen following recent publicity.
- 4.5.6 All Health Boards were able to provide the Panel with information relating to the numbers of appeals received against a decision not to provide NHS CHC and of the outcome of these appeals.
- 4.5.7 Most appeals occurred before discharge from an NHS facility, rather than when an individual was residing in a care home.
- 4.5.8 Recently, some appeals have been received posthumously.
- 4.5.9 It was unclear whether most appeals were received in writing or verbally, or through a distinct and specific appeals process other than the NHS complaints process.
- 4.5.10 A minority of Health Boards could provide clear documentary evidence of their appeals process.
- 4.5.11 Appeals were typically managed internally within each Health Board. If an appeal was received, another clinician from that Health Board with relevant experience would be identified to review the individual and make a judgement about their eligibility for NHS CHC.
- 4.5.12 Most Health Boards expressed the view that introducing a process of external review of appeals, in which a clinician from another Health Board reviewed the individual, as happened under the provisions of MEL (1996) 22, may improve perceived fairness, but would be more expensive and would cause delay and would be unlikely to alter the outcome of appeals overall.
- 4.5.13 In situations where an appeal had not been upheld, and the appellant remained unhappy with the decision, Health Boards typically managed this through the NHS complaints procedure, including referral of their decisions to the SPSO if necessary.

- 4.5.14 In the course of the review, some Health Boards asked the Panel for advice on the handling of outstanding appeals. The Panel advised that appeals needed to be dealt with under the terms of the current guidance.
- 4.5.15 Given the findings of the Review, it is likely that some individuals who meet the criteria in CEL 6 (2008) are not in current receipt of NHS CHC funding.

5. RECOMMENDATIONS

5.1 In compiling the recommendations within this report the Panel noted that:

- 5.1.1 The broad policy direction in Scotland has been to reduce the numbers of individuals who spend long periods of their lives in hospital wards.
- 5.1.2 The population served by Health Boards vary in their rurality, levels of deprivation, and demography.
- 5.1.3 There is considerable variation in the number of NHS, Local Authority, private and third sector residential and care home facilities that are available in different Health Board areas.
- 5.1.4 This variation creates a degree of geographical inequity of access to different types of care that will persist for as long as a variation in the provision of different care facilities exists.
- 5.1.5 Other aspects of the provision and funding of long term care are also inequitable, specifically the restriction of free personal and nursing care to those over the age of 65 years.

5.2 After considering the evidence gathered and feedback received, it is the Panel's belief that:

- 5.2.1 No individual in Scotland should have to live out their life in hospital accommodation, irrespective of their age, disability or financial situation. Such an arrangement should apply only where a hospital alone can meet the individual's needs.
- 5.2.2 The Scottish Government should actively seek to further minimise the numbers of individuals who have no alternative other than to live out their lives in hospital accommodation.
- 5.2.3 Only those individuals who are required to live in hospital should be exempted from charges relating to their accommodation. All other individuals, whatever their age or disability should contribute to the funding of accommodation costs, should their financial situation permit.
- 5.2.4 It is the Panel's intention that the recommendations in this report will:
 - 5.2.4.1 Support the established Shifting the Balance of Care policy to minimise the numbers of individuals who are required to live in hospital accommodation.
 - 5.2.4.2 Minimise the inequity of the location, provision and funding of long term care as far as is possible within current geographical constraints.
 - 5.2.4.3 Clearly dissociate the principles underlying the funding of health, personal and nursing care from those underlying the funding of accommodation costs.

5.3 CEL 6 (2008) and Assessment Eligibility for NHS CHC

- 5.3.1 **Recommendation 1: The Panel recommend that CEL 6 (2008) is completely revised and the term NHS CHC should be replaced with the term “Hospital Based Complex Clinical Care” (HBCCC). The choice of this term emphasises the recommendation that HBCCC should be a form of care that is only provided in facilities wholly funded and managed by the NHS.**

5.4 Eligibility and Provision

- 5.4.1 The strategic direction of care in Scotland has been to move long term care provision from hospital to non-hospital settings and the Panel believes that this direction should be continued.
- 5.4.2 However, in some Health Board areas, alternative care provision has not yet developed sufficiently and as a consequence some individuals currently remain in NHS hospital long term care simply because no alternative local provision of care is available. This happens particularly in rural areas, and may continue to be the case for the foreseeable future. The Panel’s recommendations take account of this geographical variation
- 5.4.3 **Recommendation 2: Eligibility for HBCCC should continue to be decided by specialist clinicians in partnership with a professional multidisciplinary team. No specific list of eligibility criteria, or scoring system, based on a description of an individual’s current or predicted future condition, prognosis or care needs, should form part of the guidance. For the future the primary eligibility question should simply be:**

“Can this individual’s care needs be properly met in any setting other than a hospital?”

- 5.4.4 This recommendation mirrors the manner in which many multidisciplinary teams currently assess long term care needs for individuals who cannot return home and implicitly takes into account local variations in the availability of alternative venues of care and the development of community support services.
- 5.4.5 There is currently considerable geographical variation in the availability of Local Authority, private and third sector residential and care home facilities and in the development of domiciliary support services. Clinicians and multidisciplinary teams should therefore judge the appropriateness of providing HBCCC according to their assessment of both the individual’s condition and care needs and the local alternative care provision in both domiciliary and Local Authority and private residential and nursing care facilities.
- 5.4.6 In the three island Health Board areas, where care home provision outwith the NHS is low and cannot be developed, some individuals whose care needs would be properly met in a nursing home setting in another Health Board will require to receive ongoing long term care in an NHS hospital setting or residential care with enhanced primary care support. The Panel was struck by the unique challenges of island communities and was impressed by the flexible local solutions which have been developed. Future guidance should acknowledge and encourage the innovation necessary to meet the challenges facing island Health Boards and Local Authorities.

5.4.7 The majority of individuals admitted to hospital are discharged to their usual place of residence after receiving treatment. A minority are discharged to an alternative facility usually for intermediate or long term care, and approximately 2% die before discharge. The Panel refers to care following admission, whatever the outcome, as an “episode of care”.

5.4.8 There were 1,174,117 general hospital admissions in Scotland in between 1st April 2012 and 31st March 2013. The vast majority of episodes of care (99.5%) last less than three months. However, some individuals remain in hospital care three months or longer after admission, if complex medical problems have occurred, the medical condition of the individual has never stabilised, or if rehabilitation has been challenging and not been able to be provided in any other setting.

There were 22,169 mental health admissions between 1st April 2010 and 31st March 2011 of which 14% remained in hospital for more than three months⁸.

5.4.9 The Panel believes that the most appropriate definition of HBCCC for use in a new census process should be one that is based on the length of stay of the patient in NHS facilities.

5.4.10 Recommendation 3: The current annual census should be replaced. All individuals in NHS hospital care at a point three months after admission should be considered for HBCCC unless they are a delayed discharge. At this point and every three months thereafter as necessary, a clinician and another member of the multidisciplinary team responsible for the care of the individual should assess and affirm this need on specifically designed documentation.

5.4.11 If the individual’s care needs cannot be met in a non-NHS facility, the individual should remain in HBCCC.

5.4.12 If the individual’s care needs can be met in a non-NHS facility the individual should move to such a facility in line with local and national patient choice and moving on policies⁹.

5.4.13 The Panel believes that the majority of patients who remain in hospital three months after admission will have a bona fide reason for this length of stay, most likely relating to their clinical condition and the non-availability of suitable alternative care.

5.4.14 The Panel stresses that established processes relating to choice and moving on from hospital care should be enacted at any point after admission if an individual’s care needs can be met in an alternative non-NHS facility and that the Panel is not recommending that such processes can only be put into action after three months. However, in some cases in which there is dispute about the appropriate venue of care, there is currently no agreed and documented time at which such policies can be utilised. This recommendation will standardise the approach among Health Boards in Scotland.

5.4.15 The well established national system for the audit of delayed discharges¹⁰ from hospital settings should continue unchanged and will reinforce the appropriate

⁸ ISD Scotland personal communication

⁹ http://www.sehd.scot.nhs.uk/mels/CEL2013_32.pdf

enactment of choice and moving on policies, serve to ensure that inappropriate hospital stays are minimised and that Health Boards' actions to address and reduce such stays remain a focus of health and social care agencies.

5.4.16 Recommendation 4: Health Boards and Local Authorities should determine the number of HBCCC beds that will require to be provided in their area. The Scottish Government should monitor progress towards more equitable provision than currently exists.

5.4.17 This recommendation will support the aim to reduce the number of individuals who spend long periods of their lives in NHS hospital facilities and to reduce the current inequity of provision and funding of long term care across Scotland.

5.4.18 The Public Bodies (Joint Working) (Scotland) Bill¹¹ currently being considered by the Scottish Parliament will require Health Boards and Local Authorities, working together, to develop strategic plans for their areas.

5.4.19 These plans should, in the view of the Panel, include details of the current and proposed future levels of HBCCC and other forms of non-domiciliary long-term care required to meet the needs of their population.

5.4.20 In approving the integration plans for Health Boards and Local Authorities in the integrated arrangements envisaged by the proposed legislation, the Scottish Government needs to be assured that **“the money is following the patient”** and that joint financial plans should explicitly outline the proposals to move resources to support the principle of shifting the balance of care.

5.4.21 This recommendation for some Health Boards will mean that an active programme of re-provision of continuing care facilities in domiciliary, Local Authority residential or private care home facilities will be required. Such a process has been successfully implemented in other Health Board areas.

5.4.22 HBCCC will continue to be free of charging and clinically driven as it is provided in hospital. Those in receipt of HBCCC will continue to be affected by the regulations which govern entitlement to benefit during prolonged hospital stays.

5.4.23 The current arrangements under CEL 6 (2008) allow for the provision of NHS CHC in private nursing homes. Individuals in this situation receive funding which meets all of their costs, including accommodation costs.

All people whose needs can only be met in hospital will be treated equally, have their care and accommodation provided free and have their benefit entitlement adjusted appropriately.

All people living in care homes will also be treated equally, be subject to the same charging policies and contribute to their accommodation costs depending on their individual financial circumstances.

5.4.24 The Panel believes that this position is as fair and equitable as current variations in the provision of venues for long term care can permit and will be much more easily understood than the current arrangements.

¹⁰ <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Delayed-Discharges/Guidelines/delayed-discharges-manual-120613.pdf>

¹¹ <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/63845.aspx>

- 5.4.25 The Panel recognises that the recommendations do not address the inequity in the current arrangements whereby younger adults under 65 with high levels of need do not benefit from free personal and nursing care.

5.5 Monitoring

5.5.1 **Recommendation 5: The Scottish Government should, via the new census recommended in this report, monitor the shift of long term care venues from NHS to more homely care settings in all Health Boards.**

5.5.2 The process should:

- a. Provide accurate “real-time” data on the numbers of individuals in receipt of HBCCC nationally.
- b. Provide a means by which individual Health Boards can monitor the number of patients with prolonged (more than three months) hospital stays and take steps to reduce such stays when possible and appropriate.
- c. Provide the Scottish Government with a real-time, robust and meaningful measure of the relative progress of Health Boards towards minimising the number of patients whose care is provided in an NHS hospital setting.
- d. Form a basis for forward planning for future service delivery.

5.5.3 All Health Boards should continuously collate the data produced and submit regular reports to the Scottish Government indicating:

- a. Monthly, the numbers of individuals in receipt of NHS care for a duration of three months or greater over the period of the preceding month.
- b. Monthly, a breakdown of the justification for such stays.
- c. Annually, a summary report indicating success or obstacles to progress towards the target number of NHS CHC beds for their Health Board area.
- d. At least on an annual basis, Health Boards must consider the data collected and monitor progress in implementing the agreed arrangements for HBCCC.

5.6 Information for Individuals, Relatives and Staff

5.6.1 **Recommendation 6: An easy to read document containing information on HBCCC should be made widely available to patients, carers and all health care professionals. The document should be reviewed at a minimum every three years and revised at that time if thought necessary. The document should be available in printed form, in appropriate languages and formats.**

5.7 Disputes and Appeals

- 5.7.1 The Panel heard evidence from various Health Boards that in the past the appeals process involved a degree of externality with consultants from other Health Boards invited to consider appeals. This was a lengthy, inefficient and expensive process which was not thought to have altered nor improved the initial decision making and in few instances resulted in an appeal being upheld on clinical grounds.

- 5.7.2 The Panel believes that prolonged waits in NHS hospital settings for dispute resolution are invariably detrimental to individual patient care and also result in suboptimal usage of inpatient NHS resources.
- 5.7.3 The current delayed discharge policy, choice policy and local moving on arrangements provide a framework in which most appeals and disputes are successfully resolved.
- 5.7.4 However, it is possible that some families will continue to be concerned about the most appropriate venue of care and will dispute a decision to discharge at any stage in the decision making process including the recommended three month milestone.
- 5.7.5 **Recommendation 7: When there is a dispute between an individual, their family and a multidisciplinary team about the most appropriate venue of care, the decision should continue to be reviewed on an internal basis by a clinician from the same Health Board.**
- 5.7.6 In the event of continuing dispute following internal review, the Panel recommends that the NHS complaints procedure be enacted, with the option of the complainant being able to take their grievance to the SPSO.
- 5.7.7 The Panel's recommendations would create a clear milestone for decision making regarding the appropriate type and venue of care that would exist at three months following admission to hospital. Whilst it would remain the case that most individuals' care needs and appropriate venue of ongoing care to meet these needs would be agreed by three months, this milestone would provide a clear focus for enactment of choice and moving on policies for individuals certified at that time as not requiring HBCCC.

Specific Groups

5.8 Individuals Under the Age of 65 years

- 5.8.1 Some individuals under the age of 65 years have historically had their continuing care needs met in NHS hospital settings. Such individuals typically have learning disability, mental health problems or disabling neurological disease such as demyelinating disease or motor neurone disease.
- 5.8.2 The Panel recognises that the current situation in Scotland, in which only those individuals aged over 65 years are eligible for free personal and nursing care, is unfair and inequitable. That view was also expressed by some Voluntary Organisations, who voiced concerns that the provision of free personal and nursing care is based on age rather than clinical need.
- 5.8.3 The Panel believes that there is inequity in the funding of personal and nursing care needs for individuals under the age of 65.
- 5.8.4 The Panel believes that accommodation costs for all individuals in non-NHS settings should remain subject to financial assessment irrespective of age.
- 5.8.5 **Recommendation 8: The principles and recommendations outlined in this report should apply equally to individuals of all ages.**

5.9 Terminal and Specialised Palliative Care

- 5.9.1 Terminal care is currently provided and supported by the NHS and Local Authority in NHS, Local Authority and private care venues. Hospices that provide specialist terminal and palliative care are part funded by the NHS.
- 5.9.2 The funding of patients in hospices will be unaffected, as will be the provision of domiciliary palliative care.
- 5.9.3 Patients within hospices should not be included in HBCCC numbers.

5.10 Individuals with Specific Diagnoses

- 5.10.1 The Panel has carefully considered whether specific provision should be made for individuals with specific diagnoses, such as Parkinson's disease, dementia, stroke or mental health conditions and believes that all conditions that compromise the ability of an individual to continue to live in their own home should be treated equally.
- 5.10.2 The Panel does not believe that it would be appropriate, necessary or equitable to suggest any additional recommendations for individuals who suffer with a specific medical diagnosis.
- 5.10.3 The Panel sees no logic behind a view that any group of individuals defined by a specific diagnosis should be exempt from charging policies for accommodation costs should they require non-domiciliary care at any stage.

5.11 Other Issues

- 5.11.1 **Recommendation 9: It would be unfair and unjust if those who are currently in receipt of NHS CHC are disadvantaged by the proposals and the current financial arrangements should remain for these individuals without detriment.**
- 5.11.2 In some Health Board areas this will mean that individuals in receipt of NHS CHC in care homes will continue to receive fully funded care in a care home setting.
- 5.11.3 These proposals are likely to impact on Primary Care teams and on their ability to provide sustainable, high quality care but should be in part mitigated by resource transfer. Health Boards and Local Authorities should be held to account by Scottish Government on a fair and equitable method of resource transfer.
- 5.11.4 The Panel considered in detail the significant issues that surround the transition of patients from hospital to a care home environment and the substantial impact that these issues have on the welfare of individual patients and the health care system. The Panel believes that too many patients currently reside in hospital beds for too long whilst awaiting assessments of need and the resolution of disputes relating to such assessments. The Panel further believes that the Scottish Government should consider whether exemption from all charging costs for a period of 30 days for all patients entering care homes would help to resolve some of the issues surrounding this period of transitional care.

6. SUMMARY OF RECOMMENDATIONS

Recommendation	Paragraph	
CEL 6 (2008) and Assessment Eligibility for NHS CHC		
1.	The Panel recommend that CEL 6 (2008) is completely revised and the term NHS CHC should be replaced with the term "Hospital Based Complex Clinical Care" (HBCCC). The choice of this term emphasises the recommendation that HBCCC should be a form of care that is only provided in facilities wholly funded and managed by the NHS.	5.3.1
Eligibility and Provision		
2.	Eligibility for HBCCC should continue to be decided by specialist clinicians in partnership with a professional multidisciplinary team. No specific list of eligibility criteria, or scoring system, based on a description of an individual's current or predicted future condition, prognosis or care needs, should form part of the guidance. For the future the primary eligibility question should simply be " Can this individual's care needs be properly met in any setting other than a hospital? "	5.4.3
3.	The current annual census should be replaced. Consequently, all individuals in NHS hospital care at a point three months after admission should be considered for HBCCC unless they are a delayed discharge. At this point and every three months thereafter as necessary, a clinician and another member of the multidisciplinary team responsible for the care of the individual should assess and affirm this need on specifically designed documentation.	5.4.10
4.	Health Boards and Local Authorities should determine the number of HBCCC beds that will require to be provided in their area. The Scottish Government should monitor progress towards more equitable provision than currently exists.	5.4.16
Monitoring		
5.	The Scottish Government should, via the new census recommended in this report, monitor the shift of long term care venues from NHS to more homely care settings in all Health Boards.	5.5.1
Information for Individuals, Relatives and Staff		
6.	An easy to read document containing information on HBCCC should be made widely available to patients, carers and all health care professionals. The document should be reviewed at a minimum every three years and revised at that time if thought necessary. The document should be available in printed form, in appropriate languages and formats.	5.6.1
Disputes and Appeals		
7.	When there is a dispute between an individual, their family and a multidisciplinary team about the most appropriate venue of care the decision should continue to be reviewed on an internal basis by a clinician from the same Health Board.	5.7.5
Specific Groups		
8.	The principles and recommendations outlined in this report should apply equally to individuals of all ages.	5.8.5
Other Issues		
9.	It would be unfair and unjust if those who are currently in receipt of NHS CHC are disadvantaged by the proposals and the current financial arrangements should remain for these individuals without detriment.	5.11.1

7. ACKNOWLEDGEMENTS

This review was carried out by an independent panel led by Mr Ian Anderson, Past President of the Royal College of Physicians and Surgeons of Glasgow and comprising of the following:

- Mr David Crawford, Former Executive Director of Social Work at Glasgow City Council
- Dr Andrew Elder, Consultant in Care of the Elderly, NHS Lothian Health Board
- Mr Francis McCrossin, Chartered Accountant
- Miss Susan Morrison, Project Support Officer, NHS National Services Scotland

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Health Boards:

- NHS Ayrshire and Arran
- NHS Borders
- NHS Dumfries and Galloway
- NHS Fife
- NHS Forth Valley
- NHS Grampian
- NHS Greater Glasgow and Clyde
- NHS Highland
- NHS Lanarkshire
- NHS Lothian
- NHS Orkney
- NHS Shetland
- NHS Tayside
- NHS Western Isles

Voluntary Organisations:

- Alzheimer Scotland
- Carers Scotland
- Marie Curie Cancer Care
- Parkinson's UK
- Scottish Independent Advocacy Alliance
- Spinal Injuries Scotland
- Stroke Association

Other:

- The Association of Directors of Social Work
- Mr Ron Culley, COSLA
- Mr Martin McKenna, ISD, NHS NSS

8. GLOSSARY OF TERMS

Care homes	Includes private and Local Authority nursing and care homes
Charging policies	This is the term used for Means Testing
CEL 6 (2008)	Scottish Government guidance on NHS Continuing Healthcare
COSLA	Convention of Scottish Local Authorities
Free Personal and Nursing Care	Legal entitlement for people ages 65 or over who have been assessed as having personal care needs that require services to be put in place.
Individuals	Patients, residents, clients etc
Long term	Used instead of continuing (care)
NHS CHC	NHS Continuing Healthcare
Reablement	Assistance provided for people to give them the skills necessary to be able to live in their own home independently after having spent some time in hospital
SPSO	Scottish Public Services Ombudsman
Third Sector	Comprising community groups, voluntary organisations, charities, social enterprises, co-operatives and individual volunteers - has an important role in helping the Scottish Government achieve its purpose of creating a more successful country with opportunities for all to flourish, through achieving sustainable economic growth

9. TABLE OF REFERENCES

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5.	Free Personal and Nursing Care – Consolidated Guidance	http://www.scotland.gov.uk/resource/doc/55971/0015597.pdf
6.	Intermediate care Framework for Scotland	http://www.scotland.gov.uk/Resource/0039/00396826.pdf
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