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Implementation of the National Framework for Continuing NHS Healthcare



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I have prepared this report for presentation to the National Assembly under the Government of Wales Act 2006.

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National Assembly for Wales on 13 June 2013**



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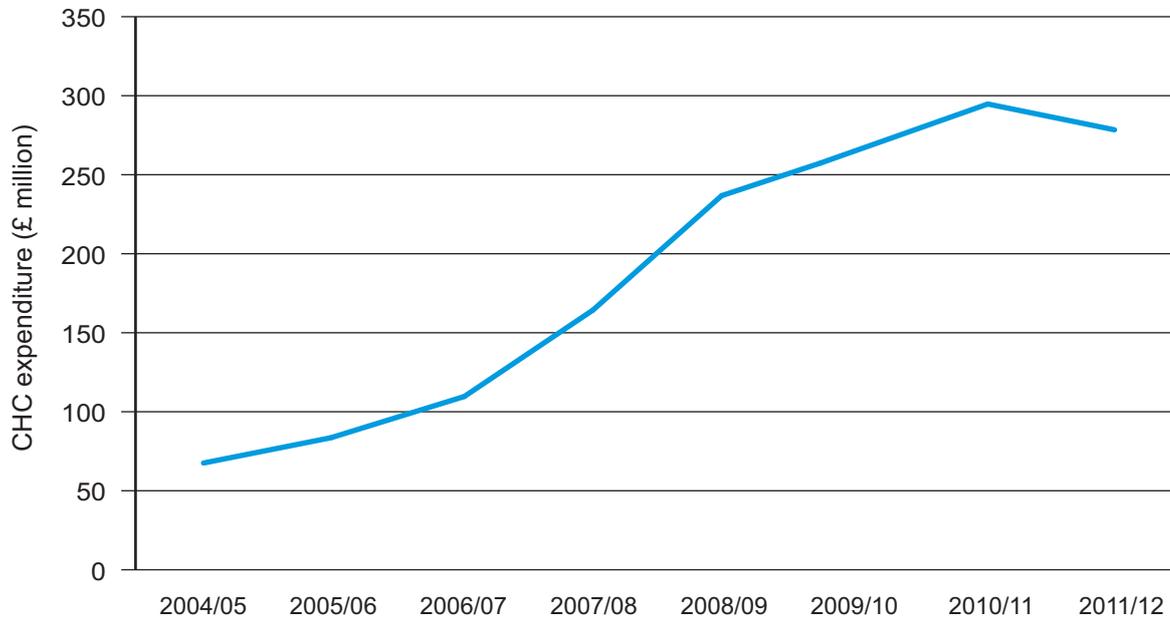
Summary

- 1 Some people need care and support over an extended period of time, as the result of disability, accident or illness. Health services are free to all at the point of delivery, but depending upon a person's needs or financial circumstances they may be charged for services provided or funded by local authorities.
- 2 When assessed as having a primary health need, people are eligible for Continuing NHS Healthcare (CHC), which is a package of care and support that is provided to meet all of the assessed needs of an individual, including physical, mental health and personal care needs. CHC is often long term, although it can be episodic in nature with some people moving in and out of eligibility. Health boards reported to us that 5,447 people across Wales were in receipt of CHC as at 31 March 2012.
- 3 When someone is eligible for CHC, the NHS has responsibility for funding the full package of health and social care. Where the individual is living at home, the NHS will pay for health care and social care, but this does not include the costs of food, accommodation or general household support. Where a person is eligible for CHC and is in a care home, the NHS pays the care home fees, including board and accommodation.
- 4 Where a person is eligible for CHC, local authorities still have continuing responsibilities. These include a role in assessment and review, providing social work services and support for carers, and meeting housing and educational needs.
- 5 If an individual is not eligible for CHC, they can still access a range of health and social care services. This can include the NHS paying for the nursing element of care provided to someone in a care home, known as NHS-funded nursing care. Health boards reported to us that 5,887 people across Wales were in receipt of NHS-funded nursing care as at 31 March 2012. However, for any care provided by social services, such as personal care and accommodation in a care home, a charge may be made depending on the person's income, savings and capital assets. Therefore, for some people a decision that they are ineligible for CHC can have a significant financial impact, with care costs being paid from their savings or from the proceeds from the sale of their home.
- 6 The funding of CHC is a significant pressure on NHS expenditure in Wales. Expenditure increased significantly from £66 million in 2004-05 to £295 million in 2010-11, before reducing for the first time to £278 million in 2011-12¹ (Figure 1). CHC expenditure now accounts for five per cent of health boards' net operating costs. Expenditure on NHS-funded nursing care over the same period has been less volatile, ranging between £32 million a year and £40 million a year. The historic increase in CHC expenditure partly reflects a number of key court judgements which have led to changes in policy guidance and eligibility criteria.

¹ Wales Audit Office analysis of health board final accounts.



Figure 1 - CHC expenditure by health boards 2004-05 to 2011-12



Note

Excludes any in-year adjustments for the potential future liabilities arising from challenges to past cases that were deemed ineligible

Source: Wales Audit Office analysis of health board final accounts 2004-05 to 2011-12

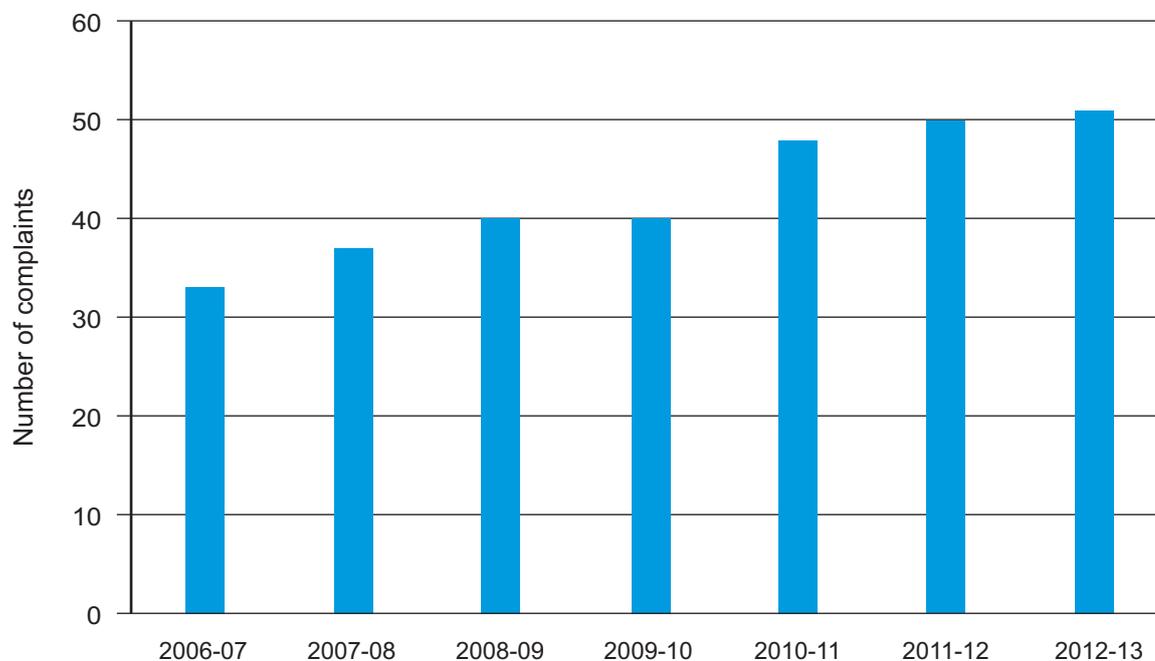
7 An ageing population with improved survival rates is also likely to result in an increase over time in the numbers of people with complex and long-term care needs. The number of people in Wales who are aged over 65 is expected to rise from 558,000 (18.6 per cent of the population) to 864,000 (25.6 per cent) by 2035.² In England, public expenditure on social services and continuing healthcare for those aged over 65 is projected to increase by 37 per cent in real terms between 2010 and 2022³.

8 There have been concerns over the consistency and fairness of decisions on eligibility for CHC, and a large number of backdated claims have been made to health boards challenging earlier decisions on eligibility. The number of complaints received by the Public Services Ombudsman for Wales relating to CHC has increased, from 33 in 2006-07 to around 50 cases in each of the last three years (Figure 2). Whilst the number of complaints has not fluctuated significantly over the last three years, the nature of the complaints has changed. In addition to complaints about eligibility decisions, the ombudsman is now receiving more complaints about the administration of some claims once eligibility has been established.

² Welsh Government Statistical Bulletin, SB 103/2011, 2010-based National Population Projections for Wales

³ Care for older people, Projected expenditure to 2022 on social care and continuing health care for England's older population, Nuffield Trust, December 2012

Figure 2 - CHC complaints received by the Public Services Ombudsman for Wales



Note

Figure for 2012-13 is a projection based on the numbers received to November 2012

Source: Public Services Ombudsman for Wales, November 2012

9 In response to funding pressures and an ageing population, the Welsh Government has taken a number of steps. These included establishing a CHC national programme board to deliver improvements in the management of CHC. The remit of the programme board included identifying opportunities for redesigning services, more cost-effective provision, and developing more robust comparative financial information on CHC. The programme board has now been disbanded and some of its responsibilities have been assumed by a National Complex Care Steering Group.

10 The Welsh Government issued a revised framework for CHC (the Framework) in May 2010, which was to be implemented by 16 August 2010⁴. The Framework covers adults and sets out the Welsh Government's revised policy for eligibility for CHC and the responsibilities of health boards and local authorities. The Framework sets out a process for the NHS, working with local authority partners, to assess health needs, decide on eligibility for CHC and provide appropriate care. The Welsh Government issued separate guidance for children and young people's continuing care in November 2012⁵.

⁴ Continuing NHS Healthcare, The National Framework for Implementation in Wales, May 2010, Welsh Assembly Government circular

⁵ Children and Young People's Continuing Care Guidance, Welsh Government, November 2012



- 11 Our examination focused on the implementation of the Framework for adults. We did not examine in any detail those aspects of the delivery of CHC, such as service redesign, that were being progressed by the programme board. When it launched the Framework in 2010, the Welsh Government made a commitment to review its operation. This report is therefore timely in informing the forthcoming Welsh Government review.
- 12 We set out to answer the question: 'Is the Framework for implementing CHC effective in ensuring individuals are dealt with fairly and consistently?' Our methodology is described in [Appendix 1](#), and we have set out a timeline of key events in [Appendix 2](#).
- 13 Overall, we concluded that the CHC Framework has delivered some improvements, but more still needs to be done to ensure that people are dealt with consistently and fairly. To help health boards better meet the requirements of the Framework, we have developed and published separately to this report a self-assessment and improvement checklist. This is intended to support individual health boards in identifying what is working well and where remedial action should be targeted.

The Welsh Government developed the CHC Framework to help ensure that people are dealt with fairly and consistently, but the Framework could be improved in a number of areas and its impact monitored more closely

- 14 **Welsh Government policy and guidance on CHC has been revised to reflect key legal judgements and to ensure people are dealt with fairly and consistently.** The first national Framework for CHC was issued in 2004, but a significant change in case law in 2006 necessitated the development of an amended Framework. There was a considerable delay in the Welsh Government overhauling the CHC Framework, with a final version issued in May 2010.
- 15 There is clear evidence of inconsistent approaches to CHC eligibility decisions across Wales before the introduction of the revised Framework. Health boards made provisions of £35.1 million in their accounts for 2011-12 for the estimated future costs arising from the challenges to CHC eligibility decisions relating to pre-Framework cases that have yet to be concluded.
- 16 The revised Framework provides detailed guidance and tools for use by health boards, and seeks to ensure fairness and consistency in assessment and decision making. Central to the arrangements is a multidisciplinary assessment of someone's care needs that informs the completion of a Decision Support Tool (DST). The DST is designed to ensure that the full range of factors that have a bearing on an individual's eligibility for CHC are taken into account in making decisions.

- 17 Some aspects of the Framework lack clarity, and there are some key differences with the approach in England.** Specific guidance on how the Framework should be applied for people with a learning disability or a mental health problem is lacking. Clearer guidance is also needed on joint funding arrangements, including for section 117 mental health patients and for people who self-fund their care, and on how health boards should monitor contracts with care homes. The Framework does not specify how performance should be monitored, and a National Complex Care Database that is being rolled out across Wales will not initially produce performance measures for CHC.
- 18** The approach to CHC varies across the UK ([Appendix 3](#)), but there is currently little difference between the approaches in Wales and England, and the frameworks in place in each country are broadly similar.⁶ We have not assessed the relevant merits of the different approaches. However, as the Framework in England has been reviewed recently, we looked to see whether any lessons could be drawn to inform the approach in Wales. In England, a screening tool is used to determine whether someone requires a CHC assessment, and adopting a similar approach in Wales could help ensure consistency in the criteria used to put people forward for a CHC assessment. Because of differences between the DST used in Wales and England, it may be more difficult for some people in Wales, most notably those with dementia, to meet CHC eligibility criteria, whilst for people with some other health conditions it may be easier.
- 19** **The extent to which the Framework or the way it has been implemented has contributed to the recent reduction in the number of CHC cases and expenditure is not clear.** CHC expenditure and the total number of CHC cases have reduced since the Framework was introduced. Across Wales CHC expenditure, having risen every year since 2004-05, fell back in 2011-12 by 5.8 per cent compared with the previous year, with five health boards experiencing a reduction, and another experiencing no substantive change. Across Wales the total number of CHC cases also reduced in both 2011 and 2012. This reduction has not been experienced in England. However, the pattern of change in the numbers of CHC cases and the number of cases per head of population is highly variable across health boards.
- 20** The extent to which the Framework itself has contributed to the recent overall fall in CHC cases and expenditure is unclear. This is because at least part of the fall is likely to reflect the £37.5 million of Welsh Government funding made available from 2008-09 for schemes to modernise complex care services; a concerted push across health boards to identify savings within CHC budgets; and the nature and extent of some hospital and community services which can impact onto the number of CHC cases.
- 21** **There is operational oversight of the Framework but strategic leadership is lacking.** A National CHC Implementation Group was established in 2010 to oversee the implementation and operation of the Framework. Given its composition and role, the group (now called the National CHC Advisory Group) is not an appropriate body to provide strategic leadership for the Framework.

⁶ The funding and charging arrangements for care and support are to change in England and the Welsh Government is considering what reforms would be appropriate for Wales; this may lead to a divergence between the two countries in coming years.



22 National leadership for CHC was previously provided through a CHC national programme. However, the programme did not have an explicit role with regard to the Framework. The lack of clear strategic leadership for the CHC Framework at a national level has been compounded by the slow progress in establishing effective successor arrangements to the national CHC programme. In particular, the National Complex Care Steering Group had had only a limited impact to date.

The Framework has delivered a number of benefits, but it has not been fully implemented across Wales and safeguards are not fully in place to provide assurance that decisions are fair and consistent within and between health boards

23 **Governance within health boards in relation to CHC has been strengthened, but provides only limited assurance that people are being dealt with consistently and fairly.** The central guidance associated with the Framework is not as detailed as the corresponding guidance in England. Over a year on from the launch of the Framework, health boards had made variable progress in developing local CHC policies and procedures. There is scope for greater sharing of policies and procedures by health boards, and for the development of all-Wales protocols and documentation.

24 Responsibilities for CHC are spread across a health board, which can lead to inconsistent approaches within a health board. Standard training on CHC and the Framework's requirements has been rolled out across Wales to mixed effect, and a broader range of training is needed. The number of hospital and community staff requiring expertise in

CHC provides an ongoing challenge to health boards.

25 Health boards cannot provide assurance that the Framework is being applied fully and that they make fair, timely and consistent decisions on eligibility both within and between their organisations. Individual cases that are deemed eligible for CHC are scrutinised, but health boards do not have arrangements in place to routinely monitor or review cases that are not put forward to be assessed for CHC or that are deemed ineligible by their staff. Also, there are no peer review arrangements between health boards.

26 **The Framework has provided a basis for more consistent assessment of care needs and decisions on CHC eligibility, although local arrangements vary across Wales and do not always meet the Framework's requirements.** There is evidence that the Framework has led to more consistent, thorough and detailed assessments of care needs. However, assessments of care needs are not always comprehensive, with input from a range of appropriate professional disciplines, and are not always undertaken at an appropriate time. The lack of engagement of GPs and hospital doctors in CHC assessment processes is a common problem. The DST is also not always being used as intended, with problems in getting the right professionals to attend meetings to discuss and agree the DST; variable standards of completion of the DST and supporting documentation; and concerns that the DST is being used too prescriptively with a lack of professional judgement being exercised.

27 Health boards have put in place scrutiny processes to ratify the conclusions of individual assessments of CHC eligibility, but some are more effective than others. Scrutiny panels are in place in all health boards but their number, scope, size and membership varies.

- 28** The Framework sets a target for the time it should take to complete the CHC assessment and decision-making process. However, there is a lack of clarity over the ‘start’ point against which timescales should be measured, health boards are not routinely measuring timescales, and our analysis of case files indicates that the target times are unlikely to be routinely met.
- 29** Fast-track processes, for the immediate provision of CHC for individuals with a rapidly deteriorating condition who may be entering a terminal phase of their lives, are generally working well. In contrast, the Framework’s requirements for planning the complex transition from children to adult CHC services are generally not being met.
- 30** **Arrangements for reviewing continuing eligibility for CHC have been strengthened, but cases are not always being reviewed as frequently or as robustly as required by the Framework.** There should be periodic review of CHC cases to determine whether an individual’s needs have changed. A change in needs should trigger an appropriate change in the package of care and an assessment of whether the person continues to be eligible for CHC funding.
- 31** Since the introduction of the Framework, health boards have made some progress in dealing with backlogs of reviews. However, CHC cases are not being reviewed in line with the frequency and timescales outlined in the Framework, which are more demanding than the corresponding requirements in England. The robustness of reviews is also highly variable, with a reluctance to move people out of CHC evident in some parts of Wales.
- 32** **The effectiveness of joint working between health and social services is highly variable.** The importance of joint working between the NHS and social services is stressed throughout the Framework, but there are significant variations in joint working arrangements across Wales. Improved joint working and communication were evident when social services attended scrutiny panels, although this is not routine practice in all health boards. Joint protocols have been developed in some parts of Wales, but in others, difficulties have been experienced in agreeing a common approach. Relationships between health and social services across Wales range from ‘positive and constructive’ through to ‘difficult’.
- 33** The number of disputes between health and social services over CHC eligibility decisions varied greatly and, although relevant policies and guidance are mostly in place, the time taken to resolve disputes is significantly longer than the target times set out in the Framework.
- 34** **There is mixed evidence on the extent to which individuals and their families are being involved in the assessment process, and processes for gaining and recording informed consent and assessing mental capacity are very inconsistent.** CHC is a complex topic with its own distinct language, and ensuring people are well informed is a particular challenge. The Welsh Government has developed a public information leaflet on CHC. However, the leaflet is not always made available, and there are gaps in information relating to consent, joint care packages and the availability of local advocacy. The Welsh Government, with Age Concern, has developed a more detailed guide for the public on the CHC process. Although health boards do not hand the guide out routinely, the guide is available online.



35 There is very mixed evidence about how well individuals⁷ are kept informed about CHC assessment and decision-making processes. The Framework confirms the requirement to obtain the informed consent of people being assessed for CHC, but the practice in obtaining consent varies across Wales. Health boards are also inconsistent in the extent to which they routinely assess and record an individual's mental capacity to give their consent and participate in decision-making processes when assessing them for CHC. There is also mixed evidence on the extent to which individuals and their families are being involved in the assessment process and, in some areas, the needs of carers are not being fully assessed.

There is a significant risk that the national project to deal with retrospective claims for CHC will not process all cases by the agreed deadline, and new backlogs of retrospective claims have developed in health boards

36 Many of the challenges around CHC eligibility have not been dealt with promptly, and although there is a longstanding deadline for clearing the cases being dealt with by a national project team, no deadline has been set for the cases that health boards are dealing with. Responsibility for dealing with retrospective claims against CHC decisions is either with a national project team, hosted by Powys Teaching Health Board, or with individual health boards, depending upon the date the claim is made.

37 In 2004, national arrangements were established that allowed people to claim retrospectively that they (or a deceased relative) had been eligible for CHC but were wrongly charged for care between 1996 and 2003. The scope of the national project has been extended over time and now covers any claim received by August 2010, the implementation date of the Framework. The Welsh Government has set a deadline that the national project should clear all these claims by June 2014.

38 Health board responsibilities for retrospective claims have changed over time, but they are now responsible for dealing with any retrospective claims received after August 2010 as well as any requests to reconsider eligibility decisions made under the revised Framework (referred to as 'disputes'). The Welsh Government has not always clearly communicated to health boards changes in their responsibilities, and has not set clear timescales for health boards to deal with retrospective claims and with disputes.

39 The national project for dealing with retrospective claims has made limited progress and, despite additional funding and reassurances from Powys Teaching Health Board that the June 2014 deadline to clear all claims will be met, in our view there remains a significant risk that the deadline will not be achieved. A failure to deal promptly with retrospective claims and disputes is unfair on the individuals concerned. Claims relating to fees dating back up to 17 years are still being dealt with by the national project. Progress by the national project in dealing with retrospective claims has been limited, with 32 per cent of claims being completed 21 months into the national project's planned lifetime of 36 months.

⁷ Throughout this report, we use the term 'individuals' to refer to people who are being, or have been, assessed for CHC as covered in the glossary.

The efficient processing of claims has been constrained by difficulties in accessing clinical records held by individual health boards and by some health boards not now accepting the original proof from a claimant that they have paid the relevant care home fees.

40 The national project has experienced significant recruitment and retention problems, and in May 2012 was projecting to complete all cases two years later than the June 2014 deadline. To ensure that the original deadline could be achieved, the Welsh Government and health boards, on a 50:50 basis, made available an additional £1.6 million to increase staffing levels in the national project team. The Welsh Government has also strengthened its monitoring of progress. However, due to continuing recruitment and retention problems, significant risks in meeting the deadline remain.

41 **Health boards are struggling to deal with the retrospective claims that they are responsible for processing.** Health boards have received large numbers of retrospective claims and further claims are likely to be made in the future. By September 2012, only 13 per cent of the 1,264 retrospective claims and disputes from individuals received by health boards since August 2010 had been concluded. Health boards have made most progress with the disputes that they have received, although these can take a considerable time to conclude. However, the majority of cases are retrospective claims and progress with these has been very slow. There is no common process across health boards for dealing with retrospective claims.

42 It is unclear whether health boards have now allocated sufficient staff resources to deal with the large number of retrospective claims and disputes in a timely way. Some health boards had originally not allocated appropriate staff resources, but as the numbers of retrospective claims and disputes has increased, all health boards have agreed to, or are considering, appointing additional staff. However, it is too soon to tell whether the increased resources are sufficient to ensure all outstanding retrospective claims will be completed in a timely way. Some health boards were also slow to set up the dispute review processes outlined in the Framework, and the independent review panels that consider disputes are not always operating effectively.



Recommendations

Guidance provided by the Framework

- 1 The Framework outlines the requirements to be met by health boards and their local authority partners in considering people for CHC. We have identified a number of areas where the current guidance could be improved, which are summarised in **Appendix 4**. We have identified opportunities for making guidance clearer or more explicit; for addressing gaps in its coverage; and for ensuring that guidance is realistic and deliverable. **We recommend that the Welsh Government, as part of its forthcoming review of the Framework, uses the findings from this report, as summarised in Appendix 4, to improve the guidance to health boards provided by the Framework.**

Leadership

- 2 Operational oversight of the implementation of the Framework is in place in the form of the National CHC Advisory Group. But stronger leadership, nationally and within health boards, is required to ensure that the Framework is implemented consistently and effectively across Wales. The National Complex Care Steering Group has had only a limited impact to date. **We recommend that the Welsh Government:**
 - a **strengthens its strategic oversight of the CHC Framework, with a focus on ensuring increased consistency in the application of the Framework and implementation of the recommendations set out in this report; and**

- b **requires health boards to allocate overall responsibility for CHC at board director level, with specific responsibility for ensuring consistency in the Framework's application across the health board, the adequacy of staff resources allocated to CHC, and effective joint working with social services.**

Fair and consistent application of the Framework

- 3 The Framework aims to ensure that individuals are considered for CHC fairly and consistently. We have identified risks that not all people who should be assessed for CHC are being identified, and that, in considering an individual's eligibility for CHC, there is potential for the inconsistent interpretation and application of the Framework within and between health boards.
- 4 To ensure that national policy and guidance further supports consistency and fairness, and in light of operating the Framework for almost three years, **we recommend that the Welsh Government:**
 - a **reconsiders the benefits of introducing a screening tool to determine whether someone requires a CHC assessment; and**
 - b **reviews the differences between the DST domains in Wales and England, particularly for cognition, to confirm that the Welsh domains are reasonable.**

- 5 To ensure consistent interpretation and application of the Framework across health boards, **we recommend that the Welsh Government:**
- a **requires health boards to establish arrangements for peer review of the processes for reaching CHC eligibility decisions, and of a sample of CHC decisions; and**
 - b **promotes a means of sharing across Wales the learning from peer reviews.**

Assessment, decision making and review

- 6 Whilst some strengths and weaknesses are common across Wales, the performance of health boards in meeting the requirements of the Framework is variable. There is also scope for health boards to learn from one another, and for common tools or documentation to be developed. **We recommend that the Welsh Government:**
- a **requires health boards to complete and action the self-assessment and improvement checklist developed by the Wales Audit Office in support of this report; and**
 - b **works with health boards to develop national protocols and documentation, for example for fast-track arrangements and for obtaining consent, and encourages greater sharing of local policies and documentation between health boards.**

Retrospective claims

- 7 The effective and consistent handling of challenges to CHC eligibility decisions is important to ensure fairness and maintain public confidence in the system. There are significant risks that the national project will not clear all retrospective claims by the agreed deadline. The position with health boards is even more uncertain, with a lack of clarity over how retrospective claims should be processed. **We recommend that the Welsh Government:**
- a **sets a deadline for the completion of all retrospective claims that are being processed by health boards;**
 - b **works with health boards to agree a detailed and common approach to dealing with the retrospective cases being processed by health boards, and ensures the approach is broadly in line with the approach adopted by the Powys project team; and**
 - c **establishes a task and finish group with executive-level representation from across all health boards and chaired by a health board chief executive, to ensure that all retrospective cases, whether these are being handled by the Powys project or individual health boards, are processed efficiently and to the set deadlines.**



Part 1 - The Welsh Government developed the CHC Framework to help ensure that people are dealt with fairly and consistently, but the Framework could be improved in a number of areas and its impact monitored more closely

Welsh Government policy and guidance on CHC has been revised to reflect key legal judgements and to ensure people are dealt with fairly and consistently

A significant change in case law in 2006 required amended guidance, but there was a considerable delay in overhauling the CHC Framework

1.1 The first national Framework for CHC and associated guidance was issued in 2004. It outlined the key criteria and issues to be taken into consideration when making decisions about eligibility for CHC. The 2004 Framework looked to address a range of issues with the provision of CHC that had been highlighted by a 1999 Court of Appeal judgment, referred to as the Coughlan judgment⁸; the Health and Social Care Act 2001, which introduced NHS-funded nursing care; and a 2003 report by the Health Service Ombudsman⁹.

1.2 A further legal judgement in 2006, referred to as the Grogan judgement, required that, in deciding upon eligibility for CHC, NHS bodies needed to have a clear process in place to assess whether there was a primary health need (Figure 3). In simple terms, an individual has a primary health need if, having taken account of all of their needs, it can be said that the main aspects or majority of the care they require is focused on addressing and/or preventing ill health.

Figure 3 - The Grogan judgement

R v. Bexley NHS Care Trust ex parte Grogan

Maureen Grogan had multiple sclerosis, dependent oedema with the risk of ulcers breaking out, was doubly incontinent, and had some cognitive impairment. After the death of her husband, her health deteriorated and she had a number of falls. Following an admission to hospital with a dislocated shoulder, it was decided that she was unable to live independently and she was transferred to a care home providing nursing care. Assessments indicated that Mrs Grogan's condition was such that she did not qualify for CHC, but did qualify for NHS-funded nursing care.

Mrs Grogan argued that the decision to deny her full NHS funding was unlawful, due in part to the level of her nursing needs indicating a primary need for health care which should be met by the NHS.

The court concluded that in assessing whether Mrs Grogan was entitled to CHC, the care trust did not have in place or apply an approach to test whether her primary need was a health need. The trust's decision that Mrs Grogan did not qualify for CHC was set aside and the question of her entitlement to CHC was remitted to the trust for further consideration.

8 The Coughlan judgement ruled on the limits of nursing care provided by local authorities for a person living in residential accommodation.

9 NHS funding for long term care, Health Service Ombudsman, February 2003

1.3 In 2006, the National Assembly issued initial guidance to NHS bodies and local authorities to help them comply with the Grogan judgement¹⁰. This was followed in December 2007 by a draft revised Framework, which was based on the Framework that had been developed in England. The draft Framework was issued in February 2008 for three months' consultation. However, the final version of the Framework was not issued until May 2010. The substantial delay reflected the need to consider a further legal judgement in August 2008, referred to as the St Helens judgement¹¹; the consequent need to circulate an amended draft of the Framework for further comment; and the limited capacity within the Welsh Government to consider the consultation responses and finalise the Framework.

There is clear evidence of inconsistent approaches to CHC eligibility decisions across Wales before the introduction of the Framework

1.4 The inconsistent application of CHC eligibility criteria was first highlighted by the Health Service Ombudsman in 2003, and subsequently by the Public Services Ombudsman for Wales through various annual reports and investigations of individual complaints.

1.5 Also, before the Framework was introduced in August 2010, there had been a large number of challenges by individuals and their families against health board decisions on CHC eligibility; these are referred to as retrospective claims. In cases where a decision that someone is ineligible for CHC has resulted in the individual funding all or part of their care home fees, there is a clear incentive to challenge the decision. More than four in every five retrospective claims

that have been concluded have been fully or partially successful, either because the application of the eligibility criteria was found to be incorrect or due to a lack of evidence to support the original decision. Health boards made provisions of £35.1 million in their accounts for 2011-12 for the estimated future costs arising from the remaining retrospective claims that had not been concluded.

The revised Framework provides detailed guidance and tools for use by health boards, and seeks to ensure fairness and consistency in assessment and decision making

1.6 The 2010 Framework sets out a process for the NHS, working with local authority partners, to assess health needs and to decide on eligibility for CHC. The Framework makes clear that the sole criterion for determining eligibility for CHC is whether a person's primary need is a health need. The Framework also sets out:

- a** training requirements and governance arrangements;
- b** how health boards should gain informed consent and ensure people have the mental capacity to give consent and make decisions;
- c** the process by which decisions on eligibility should be scrutinised by health boards;
- d** how disputes over eligibility decisions should be resolved between health boards and their partners;
- e** the arrangements to be followed when an individual wants to dispute a decision; and
- f** the arrangements for reviewing individual CHC cases over time.

¹⁰ Welsh Health Circular (2006) 046, *Further advice to the NHS and Local Authorities on Continuing NHS Health Care*, National Assembly for Wales

¹¹ The St Helens judgement confirmed that the NHS is the primary decision maker when deciding whether a person has primary health care needs.



- 1.7** Central to the arrangements is a multidisciplinary assessment process that informs the completion of a DST. The DST is designed to ensure that the full range of factors that have a bearing on an individual's eligibility are taken into account in making decisions. The tool provides practitioners with a framework to bring together and record the needs of an individual in 11 'care domains'. Most domains are subdivided into statements representing low, moderate, high, or severe level of needs; with three domains also including a priority level of need. The result of completing the DST should be an overall picture of the individual's needs, to inform decisions on eligibility.
- 1.8** The Framework is supported by a separate practice guidance document¹² that is based on frequently asked questions, and is intended to provide a practical explanation of how the Framework should operate on a day-to-day basis. As part of the latest revision of CHC policy in England, the Department of Health has now incorporated its practice guidance into the main Framework document¹³. This should help improve clarity and ensure that people using the Framework do not lose sight of the practice guidance.

Some aspects of the Framework lack clarity, and there are some key differences with the approach in England

Specific guidance and training on how the Framework should be applied for people with a learning disability or a mental health problem is lacking

- 1.9** A common view from both NHS and social service practitioners that we interviewed during the review is that the Framework is difficult to apply to people with a learning disability and, to a lesser extent, to those with a mental health problem. Unlike in England, the Framework in Wales does not include specific guidance on how the DST and primary health need eligibility test apply to people with learning disabilities.
- 1.10** At a workshop we ran for health board CHC leads, they identified the difficulties in applying the Framework to people with learning disabilities as one of their top-priority issues. This issue was also highlighted by social services staff, and one local authority commented in their survey response that 'the definition of 'primary healthcare need' is especially problematic in applying the criteria to people with learning disabilities, mental health issues and dementia'.
- 1.11** There are different care needs assessment and care planning requirements for people with a learning disability or mental health problem, which do not fit easily into the domains in the DST. Both nurses and social workers told us that, whilst the domains work well for someone with a physical health problem, they are difficult to use for someone with a learning disability or mental health

¹² *Continuing NHS Healthcare for Adults, Practice Guidance to support the National Framework for Implementation in Wales*, November 2010

¹³ *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*, November 2012 (Revised), Department of Health

problem. Nurses and social workers also told us that CHC training and support materials are focused on someone with a physical health problem, and have not been tailored for learning disability or mental health cases.

Clearer guidance on joint funding arrangements is needed, including for section 117 mental health patients and for people who self-fund their care

1.12 The Framework specifies that where a person has been deemed not eligible for CHC but requires an alternative package of care (such as NHS-funded nursing care in a care home, or a joint package of care in the community), the lead role will normally lie with the local authority. The Framework states that, in these circumstances, health boards should work in partnership with the local authority to agree their respective responsibilities in joint care packages.

1.13 Health board CHC leads attending our workshop and four social service departments in their response to our survey raised concerns about a lack of clarity about how joint packages of care should be funded. They considered that the lack of clarity can lead to inconsistent approaches to funding joint packages of care. Some agreements are based on a standard formula, such as 50 per cent of costs picked up by each organisation. Alternatively, joint care packages can be negotiated on a case-by-case basis, which can lead to disputes between organisations. Arrangements can vary within a health board area.

1.14 At our workshop, health board CHC leads also identified a need for greater clarity over joint service provision relating to one group of people with a mental health problem. Under section 117 of the Mental Health Act 1983, health and social services authorities have a duty to provide services in the community for individuals detained under certain provisions of the act following their discharge from hospital. Health and social service authorities jointly have a duty to provide these community services, referred to as after-care services, until they are satisfied that the person is no longer in need of these. At the workshop, health board CHC leads agreed that there is a lack of clarity about which services should be provided as an after-care package under section 117, and which services should be provided through CHC funding; and about how these joint packages of care should be funded.

1.15 Another area where clarity is lacking is whether people who pay for all of their care home fees, referred to as 'self-funders', should be routinely offered an assessment for CHC or NHS-funded nursing care. As a self-funder's needs and circumstances change, they may become eligible to have part or all of the costs of the care home paid by the NHS or local authority. However, there is a lack of clarity over whether people who self-fund should be routinely offered such an assessment. This issue was highlighted by the Health and Social Care Committee's inquiry into residential care services for older people¹⁴, which found that some people who self-fund receive no information or advice from their local authority, nor any assessment of their needs.

¹⁴ Residential care of older people in Wales, National Assembly for Wales, Health and Social Care Committee, December 2012



More explicit guidance about how health boards should monitor contracts with care homes is needed

- 1.16** The Framework provides some high-level guidance on the responsibilities of health boards for arranging and monitoring services, such as care home placements, to meet the needs of those with CHC. However, health board leads for CHC attending our workshop reported that contracting and monitoring arrangements are generally underdeveloped, and that more specific guidance than that currently set out in the Framework would be beneficial.
- 1.17** Such guidance could draw upon good practice examples of where robust arrangements have been put in place. For example, when Aneurin Bevan Health Board reviews cases in nursing homes, it also monitors whether the care home is providing the care package as outlined in the contract. The health board has also reviewed the trends of admissions, discharges and deaths in care homes and investigated any outlying results.

The Framework does not specify how performance should be monitored, and the National Complex Care Database will not initially produce performance measures for CHC

- 1.18** The Framework does not specify any performance indicators for CHC but states that they may be introduced for NHS organisations at some point in the future. In the absence of any national performance indicators for CHC, individual health boards have made little progress in developing local measures of performance. We found little evidence of any routine performance management information relating to CHC in most health boards.
- 1.19** Over recent years, all health boards have put in place one or more CHC databases to hold basic information on CHC cases and related costs. Health boards generally acknowledged that their databases were not fit for purpose. As a result, a task group, consisting of health board representatives supported by NHS Wales Informatics Service, has developed and is now implementing a national database. The database, referred to as the National Complex Care Database, captures CHC-related activity and costs, as well as information on NHS-funded nursing care, retrospective claims, and any joint funding arrangements in place with local authority partners.
- 1.20** NHS Wales Informatics Service rolled out to all health boards the National Complex Care Database, which is based on the version developed and used in Hywel Dda Health Board, between January and March 2013. However, the requirement to generate standardised performance information has not initially been built into the database. The task group and NHS Wales Informatics Service considered that it would be too complex to agree and develop this capability within the timescales set for the initial launch of the database.

In England, a screening tool is used to determine whether someone requires a CHC assessment

1.21 In England, a CHC screening tool is in place (Figure 4), which is designed to ensure clarity and consistency in the criteria used to put people forward for a CHC assessment. Although the screening tool in England is straightforward to complete, a screening tool has not been adopted within Wales. In the past the Welsh Government, in discussion with health boards, has concluded that a CHC screening tool is not required as the Unified Assessment Process, the common assessment process for health boards and local authorities, should identify those people who require a CHC assessment. This argument did not prevail in England, which also has a Single Assessment Process for Older People that is increasingly being used for all people over 18 years of age.

Figure 4 - Screening tool in England

Key features of the CHC checklist

A checklist has been developed in England to help practitioners identify people who need a full assessment for CHC. The checklist is based on the DST. It allows a variety of people, in a variety of settings, to refer individuals for a full assessment for CHC. For example, the tool can form part of the discharge pathway from hospital; a GP or nurse could use it in an individual's home; and social workers could use it when carrying out routine social services assessments. The intention is for the checklist to be completed as part of the wider process of assessing or reviewing an individual's needs. The checklist should also be completed when an individual requests an assessment for CHC.

1.22 The adoption of a screening tool in Wales could lead to a number of benefits. Firstly, both NHS and social services staff raised concerns with us during our fieldwork visits over difficulties they had encountered in getting colleagues to identify when someone needed to be assessed for CHC. We also identified a lack of consensus in some areas between social services and NHS staff about when a CHC assessment is needed. One local authority reported to us that they were moving towards a formal dispute with the health board over continued problems with getting people assessed for CHC. Also, some nurses told us that social services staff can be unclear as to when a CHC assessment should be triggered when there was no NHS involvement with the individual.

1.23 Secondly, health board CHC leads attending our workshop identified that the reasons in support of a decision that a CHC assessment is not warranted often are not fully documented, leaving such decisions open to the risk of challenge. The absence of a common approach to recording the consideration of whether to assess someone for CHC eligibility limits the extent to which health boards are able to monitor, and provide assurance, that people are being considered appropriately and consistently.



Because of differences between the CHC decision support tools used in Wales and England, it may be more difficult for some people in Wales, most notably those with dementia, to meet CHC eligibility criteria, whilst for some other groups it may be easier

- 1.24** The DSTs used in Wales and England are similar, with seven of the 11 care domains having the same levels of need in both countries. However, there are some differences in the highest level of need that can be recorded in Wales compared to England:
- a** the highest level of need in respect of both the mental health and continence domains in Wales is 'severe' (compared with 'high' in England); and
 - b** the highest level of need in Wales in respect of the cognition domain is 'high' (compared with 'severe' in England) and in respect of the altered states of consciousness domain is 'severe' (compared with 'priority' in England).
- 1.25** The Welsh Government told us that these differences reflected the clinical advice it had received in developing the Framework. However, there is the potential for people with similar needs to have different outcomes in terms of eligibility for CHC in Wales compared to England. This may be to the advantage of some groups but to the disadvantage of others.

- 1.26** In their written submissions to us a number of stakeholders, including Age Concern and the Alzheimer's Society, stated that people with dementia living in Wales are being disadvantaged, in terms of their eligibility for CHC, compared to their counterparts in England. The Welsh Government told us that the decision not to make available the 'severe' level of need for cognition reflected clinical advice that people in the late stages of dementia require less clinical input to their care.
- 1.27** Health boards are unable to provide accurate data on the number of CHC dementia cases over time due to the way CHC data has historically been recorded and collated. As a result, we are unable to draw firm conclusions about whether fewer people with dementia are being accepted for CHC as a consequence of the more stringent criteria used in Wales.

The extent to which the Framework or the way it has been implemented has contributed to the recent reduction in the number of CHC cases and expenditure is not clear

CHC expenditure and the total number of CHC cases have reduced since the Framework was introduced

1.28 We analysed the financial accounts of all health boards to generate data on CHC and NHS-funded nursing care expenditure since 2004-05. We also requested from health boards the number of CHC and NHS-funded nursing care cases at the end of each of the last four financial years. However, due to the way its predecessor organisations held this information, Betsi Cadwaladr University Health Board was only able to provide the relevant data for the end of 2010-11 and the end of 2011-12. As a result, our analysis of the number of CHC and NHS-funded nursing care cases before and after the introduction of the Framework focuses upon just six of the seven health boards.

1.29 Our analysis shows that CHC expenditure and the number of CHC cases have fallen since the introduction of the Framework in August 2010. Across Wales CHC expenditure, having risen every year since 2004-05, fell back in 2011-12 by 5.8 per cent compared with the previous year (Figure 1 on page 5). Five health boards experienced a reduction in 2011-12, one (Powys Teaching Health Board) experienced no substantive change, and one health board (Cardiff and Vale) experienced an increase.

1.30 Across the six health boards that were able to provide the relevant data, the number of CHC cases at the year-end reduced in both 2010-11 and 2011-12 (Figure 5). However, the pattern of change in the numbers of CHC cases at year-end varied between the six health boards, and the number of CHC cases at Betsi Cadwaladr University Health Board increased by 5.9 per cent between 31 March 2011 and 31 March 2012.

1.31 The reduction of CHC cases has not been experienced in England, where data is reported on the number of people in receipt of CHC each quarter¹⁵. Overall, this data shows a steady increase of CHC cases between 2009 and 2012; with an increase of 5.6 per cent in the number of cases between the fourth quarters of 2009-10 and 2010-11, and an increase of 4.5 per cent between the fourth quarters of 2010-11 and 2011-12. Seven of the 10 strategic health authority areas experienced an overall increase between March 2009 and March 2012.

Expenditure on NHS-funded nursing care has fallen marginally since the Framework was introduced, but the number of cases at year-end has increased

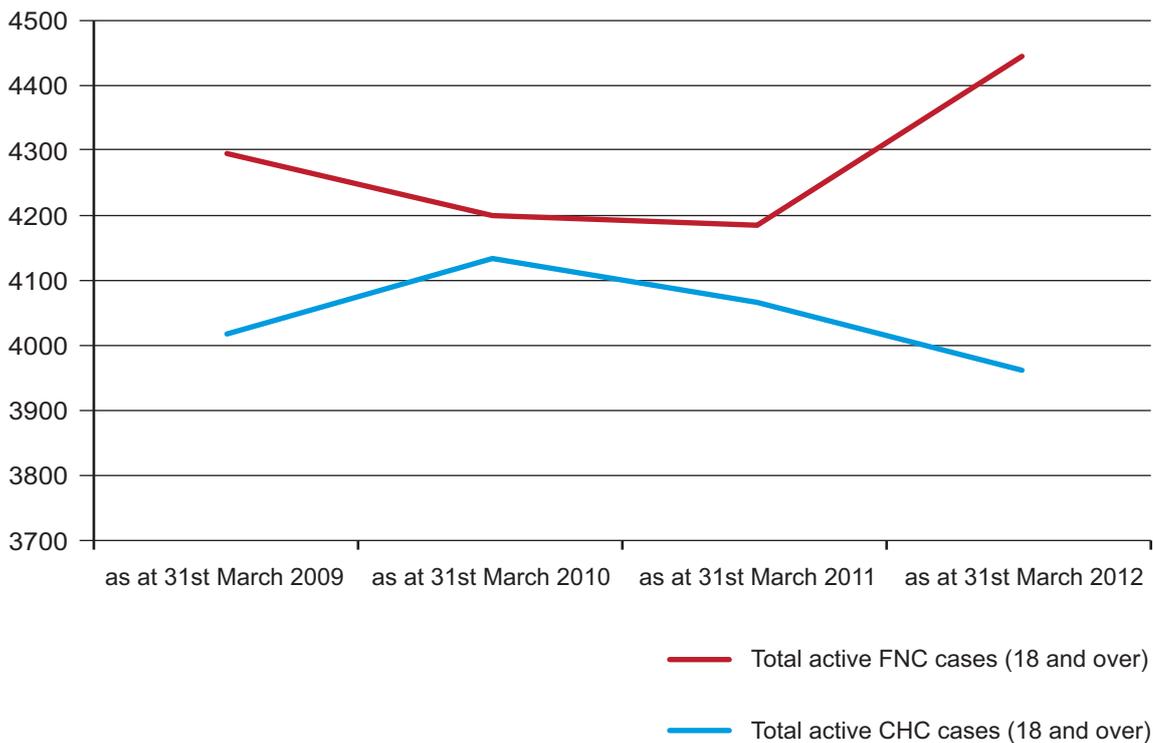
1.32 We also examined patterns of NHS-funded nursing care expenditure and case numbers to compare these to CHC patterns. We found that expenditure on NHS-funded nursing care also reduced in 2011-12, but by only 0.3 per cent, and that between 2009-10 and 2011-12 the increase in expenditure on NHS-funded nursing care (13 per cent) was greater than the increase in expenditure on CHC (7.8 per cent).

¹⁵ The latest data on CHC numbers was released by the Department of Health on 21 January 2012, www.dh.gov.uk/health/2013/01/nhs-continuing-healthcare/



1.33 Across the six health boards that were able to provide the relevant data, the total number of CHC and NHS-funded nursing care cases at year-end increased from 8,355 in 2010 to 8,412 in 2012, an increase of 1.9 per cent (Figure 5). This reflected a reduction of 171 CHC cases (a fall of 4.1 per cent), and an increase of 248 NHS-funded nursing care cases (a rise of 5.9 per cent).

Figure 5 - Number of CHC and NHS-funded nursing care cases between 31 March 2009 and 31 March 2012 across six health boards



Note

Data excludes Betsi Cadwaladr University Health Board as it could not provide the number of CHC and NHS-funded nursing care cases for 31 March 2009 and 31 March 2010.

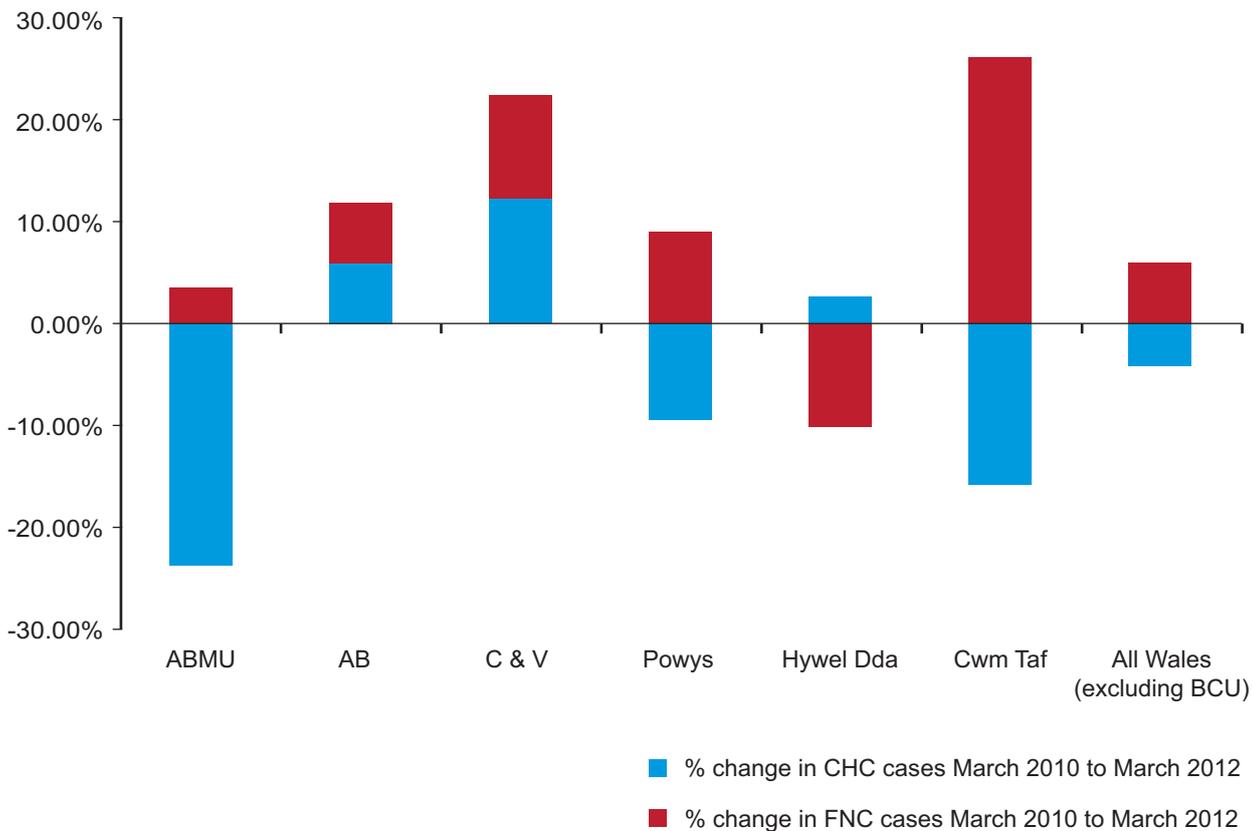
Source: Wales Audit Office survey of health boards, May 2012

The pattern of change in the numbers of CHC and NHS-funded nursing care cases and the number of cases per head of population is highly variable across health boards

1.34 The overall pattern of change in the numbers of CHC and NHS-funded nursing care cases between March 2010 (the year-end before the Framework was introduced) and March 2012 is highly variable between health boards (Figure 6), with:

- a** the number of CHC cases increasing by 12 per cent in Cardiff and Vale University Health Board, but reducing by 24 per cent in Abertawe Bro Morgannwg University Health Board;
- b** NHS-funded nursing care cases increasing in all health boards with the exception of Hywel Dda Health Board which experienced a 10 per cent reduction; and
- c** three health boards experiencing some level of reduction in CHC cases and an increase in NHS-funded nursing care cases.

Figure 6 - Percentage change in CHC and NHS-funded nursing care cases between March 2010 and March 2012 by health board



Note

Data excludes Betsi Cadwaladr University Health Board as it could not provide the number of CHC and NHS-funded nursing care cases for 2010.

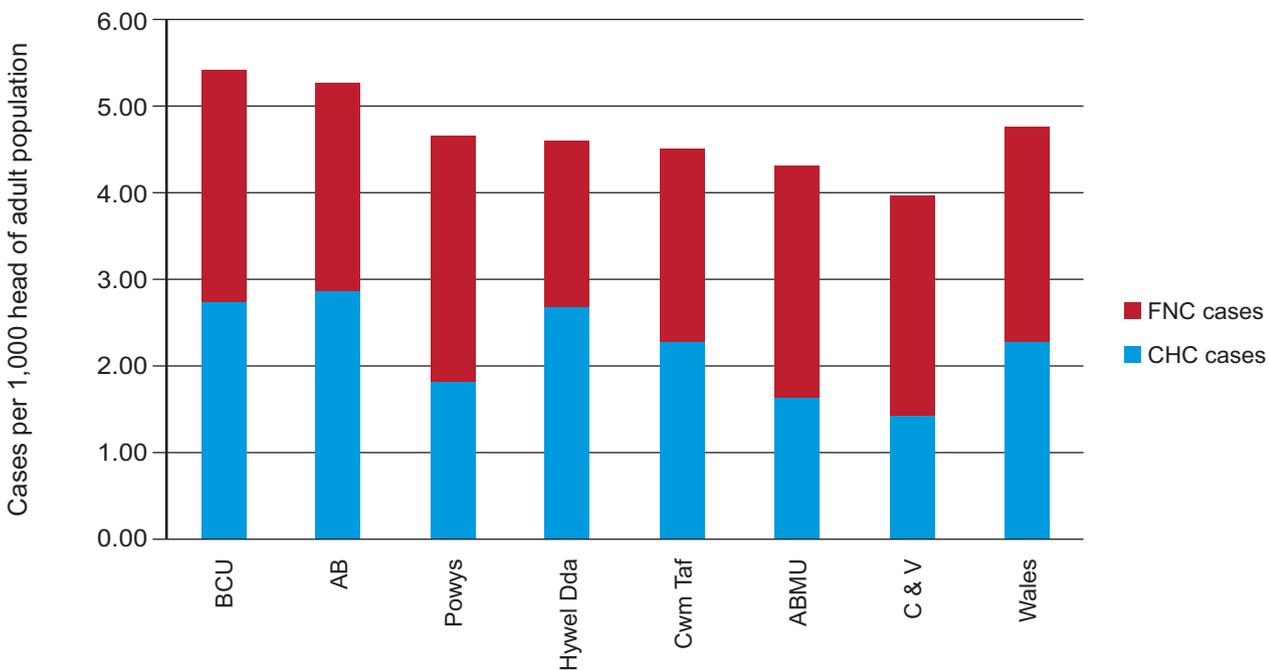
Source: Wales Audit Office survey of health boards, May 2012



1.35 There are also highly variable year-on-year patterns between health boards in the number of CHC and NHS-funded nursing care cases. In some health boards, there has been a consistent year-on-year pattern. Cardiff and Vale University Health Board has experienced a year-on-year increase in CHC cases between March 2009 and March 2012; in Abertawe Bro Morgannwg University Health Board, CHC cases have declined and funded nursing cases increased in each of these years; and in Hywel Dda Health Board, NHS-funded nursing care cases have reduced in each of these years. In other health boards the overall changes between 2009 and 2012 are underpinned by fluctuating year-on-year patterns.

1.36 Finally, the number of CHC and NHS-funded nursing care cases per head of adult population varied across health boards (Figure 7). For example, the Welsh Health Survey¹⁶ identifies Cwm Taf Health Board as having the adult population with the poorest general and mental health, which would suggest that the health board should have relatively high numbers of CHC and NHS-funded nursing care cases. However, Cwm Taf Health Board has only an average proportion of CHC cases and a below-average proportion of NHS-funded nursing care cases per head of adult population.

Figure 7 - Total active CHC and NHS-funded nursing care cases per 1,000 head of population aged 18 and over at 31 March 2012



Source: Wales Audit Office survey of health boards

¹⁶ Welsh Health Survey 2010 and 2011, Local Authority/Local Health Board Results, SB 86/2012, 19 September 2012, Welsh Government

There are a number of reasons that could explain the overall fall in CHC cases and expenditure and the variable patterns across health boards

- 1.37** The patterns of expenditure and case numbers before and after the introduction of the Framework indicate that, if all other things were equal, the Framework might have resulted in the application of more stringent CHC eligibility criteria. However, the extent to which the Framework itself has contributed to the recent overall fall in CHC cases and expenditure is unclear. The Framework was developed to ensure decisions on CHC eligibility were more consistent across Wales and in line with legal judgements, but it was not an expressed aim of the Framework to reduce CHC expenditure by making it harder for people to qualify for CHC. However, the need to achieve greater consistency suggests that some cases that previously would have been deemed ineligible would, post-Framework, be accepted for CHC, and vice versa.
- 1.38** Following NHS reorganisation in October 2009, some health boards had already taken steps to improve the consistency of decisions on eligibility for CHC and NHS-funded nursing care. For example, in our discussions with Abertawe Bro Morgannwg University Health Board, it told us that following the NHS reorganisation it became apparent that there was inconsistent interpretation and application of CHC and NHS-funded nursing care eligibility criteria across the former local health board areas within the new organisation. The health board told us that it had taken steps to address these inconsistencies, which would have had an impact on the numbers of cases
- now accepted as eligible for CHC. However, there remains the risk of inconsistency between different health boards. The Welsh Government has not established any means of monitoring whether health boards are interpreting and applying the Framework consistently.
- 1.39** From 2008-09, the Welsh Government made available £37.5 million for schemes across Wales that were intended to modernise services and develop and implement new service models. These schemes focused on people with long-term complex health and social needs, and included the development of complex care teams, integrated intermediate community care services, reablement services and community palliative care services. The Welsh Government undertook an internal evaluation of these schemes between October and December 2010. The evaluation highlighted a lack of quantitative data, but concluded that the majority of the schemes reviewed either contributed to reducing the need for CHC or enabled more people to leave CHC.
- 1.40** The reduction in CHC expenditure also followed a concerted push across health boards to identify savings within CHC budgets. Our report on *Health Finances*¹⁷ identified that health boards reported £44 million of savings on CHC expenditure in 2011-12, accounting for the third-largest area of savings. Our follow-up report on adult mental health services¹⁸ illustrated how more cost-effective service provision has been pursued, for example, by moving people out of high-cost, CHC-funded mental health placements in the independent sector into newly developed local services.

¹⁷ *Health Finances*, Wales Audit Office, July 2012

¹⁸ *Adult Mental Health Services Follow up Report*, Wales Audit Office, July 2011



1.41 Our discussions with health boards identified a number of other factors that could explain the variable patterns between health boards. Although there is a lack of data to quantify the impact of these factors, it is reasonable to assume that the following will have affected the number of CHC cases to some degree:

- a** the differing levels of need for CHC and NHS-funded nursing care across Wales;
- b** the nature of NHS hospital-based services, for example having a high number of long-term or rehabilitation beds will reduce the numbers of CHC placements needed in care homes, and thereby reduce the number of CHC cases and expenditure;
- c** the extent of community-based services provided by the NHS or local authorities, such as those focused on maintaining independence or providing end-of-life care, will reduce the numbers coming into CHC;
- d** the extent of care home beds available in the independent sector; and
- e** some health boards also told us that the new Framework was a stimulus to address the previous lack of regular and robust reviews of CHC cases, which resulted in some people moving out of CHC eligibility.

There is operational oversight of the Framework but strategic leadership is lacking

A National CHC Implementation Group has overseen the implementation and operation of the Framework

1.42 A National CHC Implementation Group was established in 2010. Its main functions were operational in nature, and included overseeing the implementation of the Framework and the provision of associated training; where appropriate, promoting consistent approaches across health boards; and sharing issues of concern and best practice. The National CHC Implementation Group operated independently from the Continuing NHS Healthcare National Programme, which provided leadership on how to improve the management of CHC.

1.43 The group consisted of lead CHC nurses from health boards, the older people's lead from the Welsh Local Government Association, and the Welsh Government policy lead and policy advisor for CHC. The group is now called the National CHC Advisory Group. It continues to be chaired by a lead CHC nurse from a health board, and its focus now includes:

- a** considering issues which health board leads can progress on an all-Wales basis to ensure consistency of approach and process;
- b** providing a peer review and support function as required;
- c** supporting and informing the pending Welsh Government review of the 2010 Framework, and to consider the recommendations arising out of this Wales Audit Office report; and

- d providing advice, guidance and local intelligence to the Welsh Government regarding CHC delivery and the implementation and application of national policy.

1.44 The National CHC Advisory Group continues to have representation from health board CHC lead nurses, as well as the Welsh Government's policy lead and policy advisor for CHC. A representative from local government, with corporate responsibility for social services, also attends. However, given its composition and role, the National CHC Advisory Group is not an appropriate body to provide strategic leadership for the Framework. The group also has no explicit role in monitoring the consistent interpretation and application of the Framework across health boards.

There has been a lack of clear strategic leadership for the CHC Framework, and this is compounded by the slow progress in establishing effective successor arrangements to the national CHC programme

1.45 The Continuing NHS Healthcare National Programme was established in July 2010 as one of the delivery mechanisms in support of the Welsh Government's *Five-Year Service, Workforce and Financial Strategic Framework*¹⁹. The CHC national programme board was intended to provide leadership and a nationally co-ordinated approach to CHC. However, the board did not have an explicit leadership role in respect of the Framework, although a number of its initiatives related to or supported elements of the Framework. Nor did it have a role in monitoring the consistent interpretation and application of the Framework across health boards.

1.46 All national programmes in support of the Welsh Government's *Five-Year Service, Workforce and Financial Strategic Framework*, including CHC, were ended during the final quarter of 2011. The CHC national programme was succeeded by a National Complex Care Steering Group which held its inaugural meeting in January 2012. One of the priorities for the National CHC Advisory Group was to clarify its relationship with the National Complex Care Steering Group, which has the potential to provide a strategic leadership role. However, this clarity has not been achieved as the steering group has made little progress and has had little impact to date:

- a it is chaired by a health board director of primary, community and mental health, whereas the CHC national programme board had been chaired by a health board chief executive;
- b whilst a paper outlining the proposed role of the National Complex Care Steering Group has been developed, the group has no formal terms of reference;
- c a detailed project plan has not been developed as had been intended; and
- d following its inaugural meeting, the steering group has not met subsequently, with all four planned meetings being cancelled.

¹⁹ *Delivering a Five-Year Service, Workforce and Financial Strategic Framework for NHS Wales*, Welsh Assembly Government, June 2010



Part 2 - The Framework has delivered a number of benefits, but it has not been fully implemented across Wales and safeguards are not fully in place to provide assurance that decisions are fair and consistent within and between health boards

Governance within health boards in relation to CHC has been strengthened, but provides only limited assurance that people are being dealt with consistently and fairly

Since the launch of the Framework, health boards have made variable progress in developing local CHC policies and procedures

- 2.1** The Framework required health boards and their partners to review their operational processes to ensure they comply, and to have in place relevant policies and guidance. Reference is made in various sections of the Framework to the need to develop specific policies or protocols, such as for handling disputes with local authorities over CHC eligibility decisions. These requirements are intended to help ensure that the Framework is consistently applied across primary, community and hospital services, and to help ensure staff are clear about local arrangements for implementing the Framework. The revised CHC Framework in England²⁰ is more prescriptive than the Welsh Framework, and includes a detailed and comprehensive list of what should be included in local protocols and procedures.
- 2.2** More than one year on from the implementation date of the Framework, health boards had made variable progress against the Framework's requirements to review their policies and processes. In response to our surveys, all health boards and most local authorities stated that they had reviewed their operational processes to ensure they comply with the Framework. However, Powys Teaching Health Board had not reviewed its discharge processes, and two of the 17 local authorities that responded to the survey had not considered the extent to which their existing practices complied with the Framework.
- 2.3** During the last quarter of 2011, we examined a range of documents from health boards. These showed that the progress made in developing local CHC policies and protocols varied substantially between health boards. Aneurin Bevan Health Board had a well-developed range of agreed policies and protocols, but in some other parts of Wales policies were still in draft form, and were not always comprehensive and detailed.
- 2.4** All seven health boards had some form of operating policy or procedure for CHC, typically a version of the Framework document that had been amended to reflect local arrangements. However, in four health boards operational policies were still in draft. The extent to which local arrangements were set out in detail also varied between health boards.

²⁰ National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, November 2012 (Revised), Department of Health

- 2.5** Where they had been developed, local CHC policies were not always comprehensive. Our review of health board CHC policies (including those still in draft) identified that they did not prescribe local arrangements for:
- a** the transition from children to adult services in six health boards;
 - b** resolving disputes between organisations over CHC eligibility in one health board; and
 - c** an independent review panel to consider disputes from individuals against CHC decisions in one health board.
- 2.6** During our fieldwork visits and at the workshop for health board CHC leads, we were told of a number of reasons why some health boards had made only limited progress in developing policies and procedures. These included limited staff capacity to deal with the CHC agenda, organisational changes following NHS restructuring, and the large number of local authority partners that they needed to consult.
- 2.7** We found some examples of health boards learning from one another through sharing policies. For example, the fast-track policy (for people who need to be considered for CHC because of a rapidly deteriorating condition) that was developed by Aneurin Bevan Health Board has been adopted by Hywel Dda and Abertawe Bro Morgannwg University Health Boards.
- 2.8** However, there is further scope for sharing policies and procedures across Wales, not least to help ensure the consistent application of the Framework. Some health boards support the development of standardised all-Wales assessment forms and related documentation, to help reduce the variability of assessment across Wales and to incorporate the best elements of current practice. There is also potential for further development of all-Wales protocols, for example in England there is a national fast-track pathway²¹.
- 2.9** In the three health board areas we visited, the documentation used to support assessments varied, and each had different strengths and weaknesses. For example, Aneurin Bevan Health Board had useful prompts to record progress with carer assessments; and Betsi Cadwaladr University Health Board had comprehensive consent and capacity forms and prompts for whether the individual and their family have been informed of the potential financial implications of the CHC assessment. The documentation used to support other stages of the CHC process, such as for scrutiny panels and reviews, also varied between the three health boards.
- Responsibilities for CHC are spread across a health board, which can lead to inconsistent approaches within a health board**
- 2.10** All health boards have a lead for CHC who is supported by a central or dedicated team of staff. The teams vary in size and their role is to develop and oversee local policy and its implementation, and provide training and support to front-line staff. They have a key role in ensuring a consistent approach to dealing with CHC across the health board. They will also often be involved in the processes for dealing with disputes over CHC eligibility decisions and handle any CHC-related complaints.

²¹ Fast Track Pathway Tool for NHS Continuing Healthcare, November 2012 (Revised), Department of Health



2.11 CHC assessments are undertaken in hospital or community settings by front-line staff, such as nurses and therapists, working within operational teams. Teams can be based, for example, around clinical groupings or geographic localities. Operational teams hold the budgets for CHC and function independently of the dedicated CHC team. Nurse assessors, who undertake CHC and NHS-funded nursing care assessments and reviews of people in care homes, may be part of the front-line operational teams or be part of the dedicated CHC team.

2.12 The dedicated CHC team and the operational teams within a health board need to be clear on their respective responsibilities and to work together effectively. In two of the three health boards we visited, we found inconsistent practices in implementing the Framework within the health board area. For example, at the time of our fieldwork, the dedicated CHC team in Hywel Dda was taking steps to address inconsistencies between the procedures and practices being applied across the three operational areas within the health board.

2.13 In Betsi Cadwaladr University Health Board, operational management of CHC is centred on clinical programme groups. One clinical programme group has developed a CHC procedure in addition to the health board-wide CHC procedure, which has led to staff completing duplicate forms. The operational staff we interviewed as part of our fieldwork were confused as to which procedure to follow and which documents to complete. Also, at that time the dedicated CHC team reported that:

- a** there was an incentive for clinical programme group staff to move any dispute with local authority partners through the informal resolution stage, as the dedicated CHC team would then take over responsibility once the formal dispute stage was reached; and
- b** the dedicated team had responsibility for handling disputes made by individuals against an eligibility decision, but clinical programme group staff could place a low priority on undertaking any review or reassessment that was required.

Standard training has been rolled out across Wales to mixed effect, a broader range of training is needed, and the number of hospital and community staff requiring expertise in CHC provides an ongoing challenge

2.14 The Framework stipulates that all relevant health and social care staff should be made aware of the new guidance and procedures through appropriate training. Training was to be provided to all members of the multidisciplinary team in hospital involved in hospital discharge, as well as community-based professionals involved in assessing the need for, and planning of, long-term care.

2.15 The Welsh Government developed with stakeholders an all-Wales NHS Continuing Healthcare training programme for NHS and social services staff, to be run by health boards across Wales. The one-day training programme generally received positive feedback from the health and social service practitioners we interviewed during our fieldwork visits. Eight of the 18 local authorities that responded to our survey also referred to the benefits of joint training in responding to our question on what they saw as the main successes in implementing the Framework. However, in part of Hywel Dda Health Board area, the training had been reduced to a half-day session.

2.16 An additional half-day follow-up course on the Framework had been run in two of the health boards we visited, and was about to be rolled out in the third. In addition, Aneurin Bevan Health Board has developed specific training on fast-track procedures and on conflict resolution. Training materials on multidisciplinary team working are also available on the all-Wales complex care forum website²².

2.17 Our surveys of health boards and social services departments identified that arrangements for monitoring which staff have received CHC training are highly variable across Wales. Three out of seven health boards and two out of the 16 responding local authorities (two local authorities did not answer this question) reported that they did not have readily available a record of which staff had received training on the new CHC

Framework. The absence of monitoring makes it difficult to identify and target staff who have not received training.

2.18 In our surveys, we also asked health boards and social services departments to estimate the proportion of relevant staff who had received training on the new Framework. Their responses indicate that, across Wales, there are still considerable numbers of staff who have not yet received the relevant training (Figure 8). At our workshop, health board CHC leads told us that attendance at the standard CHC training day has been dominated by nursing and social services staff, with few GPs or medical staff attending. No health board has made training in CHC mandatory for relevant staff, although health board CHC leads told us that they expect it to be taken up by appropriate staff.

Figure 8 - The estimated proportion of different staff groups that have received CHC training

	Number of health boards estimating the percentage of staff trained				Did not respond
	0-25%	26-50%	51-75%	76-100%	
Multidisciplinary team members involved in hospital discharge	0	3	3	0	1
Community-based professionals involved in assessing the need for, and planning of, long-term care	0	2	3	1	1
	Number of local authorities estimating the percentage of staff trained				Did not respond
	0-25%	26-50%	51-75%	76-100%	
Hospital-based social workers	0	0	5	11	6
Community-based social workers	0	0	9	8	5

Source: Wales Audit Office survey of health boards and social services departments, October 2011

²² The Complex Care Forum was developed as part of the national CHC programme and facilitates shared learning and provides a forum for debate around complex care and CHC.



2.19 The need for further training around CHC was widely recognised by the managers and staff involved in CHC who we interviewed.

A common view from health board CHC leads was that, despite the training that has been provided, staff can still be confused about when to assess someone for CHC and how to apply the primary health need approach. In addition, health board CHC leads and the health and social services practitioners we interviewed raised with us some specific areas where further joint training is needed. These included training in the application of the DST to support consistent decision making, chairing skills for those running multidisciplinary meetings (which health board CHC leads identified as one of their top priorities), and conflict resolution and managing difficult situations.

2.20 Ensuring that all relevant staff develop an appropriate level of expertise through initial and ongoing training is a particular challenge for health boards. For example, there were 945 district nurses across Wales in 2011, with Cardiff and Vale University Health Board employing the highest number at 248 district nurses²³. We estimate that for Cardiff and Vale University Health Board to ensure that just this group receives annual training would require around two training sessions per month throughout the year.

2.21 There are alternative ways of developing expertise around CHC that may be more practical than training a large number of staff, many of whom will not be dealing with CHC cases on a regular basis. Some health boards have developed specialist front-line posts for CHC. At one of the district general hospitals

in Hywel Dda, a single nurse completes all CHC DSTs. This person is well trained and experienced in CHC, and CHC and nursing staff told us that the post was resulting in more robust and consistent CHC assessments. Developing and extending this approach across Wales and into other service areas could provide a more efficient and effective way of dealing with the challenges faced in developing a workforce with expertise in CHC. Training up CHC leads within district nursing or mental health services may also be more efficient than seeking to develop expertise across all team members.

Although there is scrutiny of individual cases that are assessed as eligible for CHC, health boards cannot provide assurance that the Framework is being applied fully and that they make fair, timely and consistent decisions both within and between their organisations

2.22 The Framework makes it clear that health boards are responsible for ensuring consistency, in terms of their decisions on eligibility for CHC. But, in the absence of robust monitoring and audit, health boards cannot provide assurance that within their organisation potential cases are being put forward for assessment, and are subsequently assessed, on a consistent basis. The Framework states that health boards:

- a** should use effective auditing to monitor and ensure there is no discrimination on the grounds of race, disability, gender, age, sexual orientation, religion or belief, or type of health need (for example, whether the need is physical, mental or psychological)²⁴; and

²³ StatsWales, 2011

²⁴ This requirement is now embedded in the Equality Act 2010, which came into force after the Framework was published and includes nine 'protected characteristics' – these are the grounds upon which discrimination is unlawful. The characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

- b** may wish to improve practice and ensure a consistent application of the Framework by reviewing the pattern of recommendations made by the multidisciplinary teams (separately from the approval of recommendations in respect of individual cases).
- 2.23** All health boards have scrutiny panels which examine individual cases that have been deemed eligible for CHC by multidisciplinary teams. Scrutiny panels also commonly cover NHS-funded nursing care cases. However, we found that scrutiny and monitoring processes, covering all potential CHC cases, are not well developed:
- a** apart from processes invoked as a result of disputes and complaints, health boards do not have arrangements in place to routinely monitor or review cases that are not put forward for CHC assessment or are deemed ineligible by multidisciplinary teams;
 - b** only three health boards reported any internal or clinical audit of CHC processes; and
 - c** only Abertawe Bro Morgannwg University Health Board reported having reviewed over time the pattern of eligibility recommendations from multidisciplinary teams.
- 2.24** In the absence of any peer review arrangements between health boards, they also cannot provide assurance that the Framework is being consistently interpreted and applied between health boards. During our review, some health boards told us that they have been addressing inconsistencies in the interpretation and application of CHC criteria across former local health board areas that they now cover. Peer review would help establish whether similar inconsistencies between health boards exist.
- 2.25** The need to provide assurance about the consistent application of the Framework, both within and between health boards, is particularly important given the risk that financial pressures could impact upon eligibility decisions. In our survey of social services departments, we asked about the issues that had the potential to undermine the effective implementation of the Framework. Four authorities made specific reference to the financial pressures faced by public bodies and the perception that this is influencing decisions on eligibility.



The Framework has provided a basis for more consistent assessment of care needs and decisions on CHC eligibility, although local arrangements vary across Wales and do not always meet the Framework's requirements

The assessment of an individual's care needs is not always undertaken at an appropriate time and is not always comprehensive

2.26 The Framework states that once a decision has been made to consider someone for CHC, the first stage should be to undertake a full assessment of the person's care needs. CHC health board leads at our workshop told us that the Framework has led to more consistent, thorough and detailed assessments of care needs. However, the assessment requirements outlined in the Framework are not being met consistently.

2.27 The Framework states that 'the multi-disciplinary team carrying out an assessment for CHC should always consider whether all available interventions that may impact on health needs have been implemented and whether there is further potential for rehabilitation and regaining independence, and how the outcome of any treatments or medication may affect on going needs'. The Framework goes on to state that: 'Assessments in acute settings can sometimes poorly represent an individual's capacity to maximise their potential. Similarly, assessments conducted in poor quality care environments may also artificially inflate health care needs.'

2.28 In our survey of health boards, we asked whether it was routine practice that at the outset of the CHC assessment process, consideration was given to whether any further steps could be taken to improve the condition and independence of the individual in the immediate term. We found that:

- a** only two health boards stated that this practice was routine 'in all cases';
- b** four health boards stated that the practice occurred 'in most cases'; and
- c** one health board stated that the practice occurred only for 'some cases'.

2.29 At our workshop, some CHC health board leads told us that some patients are being assessed for CHC in acute settings inappropriately, because a focus on reducing the length of hospital stays and delayed transfers of care creates pressure on nurses to undertake assessments at too early a point in their recovery.

2.30 The Framework states that a comprehensive, multidisciplinary assessment of a person's care needs should be carried out and that this should include separate assessments by all relevant specialist and non-specialist staff. Depending upon the individual's circumstances, assessments may be required from nurses, therapists, GPs, consultants and social workers. However, in their survey responses, just three health boards stated that: 'In all cases' a comprehensive assessment of health and social care needs had taken place prior to the completion of the DST. The remaining health boards stated that this was the case 'most of the time.'

- 2.31** In their survey responses, health boards identified a particular problem in obtaining assessments from GPs. Either they were not being regularly completed or, when provided, they contained very limited information.
- 2.32** In two of the three health boards we visited, Betsi Cadwaladr and Hywel Dda, the assessments of care needs we examined as part of our case file reviews were largely restricted to nursing assessments. For example, in Betsi Cadwaladr University Health Board, three out of every four case files we examined included only a nursing assessment, and GP and consultant input was typically limited to signing their agreement to the recommendation arising from the assessment process.
- 2.33** In the third health board, Aneurin Bevan, more thorough multidisciplinary assessments of care needs, with input from nurses, therapists and social workers, were routinely to be found in the case files we examined. Many case files also evidenced input from GPs and consultants, although the time taken to obtain GP and consultant input frequently led to a delay in completing the assessment process. In addition to the nursing assessment, nine out of every 10 case files we examined contained an assessment from at least one other professional.
- 2.34** During our discussions with health board CHC lead nurses, some questioned the need to always seek an input to the assessment process from a GP, for example when an individual has not been in contact with their GP for some time. These health boards would like the Framework to be explicit about when it might be appropriate to exclude certain professionals from the assessment process.

The DST is intended to increase the consistency and transparency of decisions on eligibility for CHC, but some professionals consider it to be too long and repetitive, and it is not always being used as intended

- 2.35** The Framework states that once all assessments of care needs have been undertaken and collated, the multidisciplinary team should meet to complete the DST and determine eligibility for CHC. The CHC leads, nurses and social workers that we interviewed during fieldwork were generally supportive of the DST, which they considered helped to improve the consistency of decision making. At our workshop, CHC health board leads considered the increased transparency of decision making provided by using the DST to be one of the main benefits that the Framework has delivered.
- 2.36** However, health boards, social services departments and providers of advocacy services raised a number of concerns about the DST, and the most frequently reported concerns about the Framework from local authorities were about the DST. Half of local authorities that responded to our survey expressed concerns about the DST, including:
- a** it being too long, complex and repetitive, taking three hours or more to complete;
 - b** it not fitting well alongside the Unified Assessment Process used by health boards and local authorities, because the two processes use different domains or areas of assessment; and
 - c** it not fitting well alongside assessments used by mental health and learning disabilities services, especially in relation to the three psychological domains of the DST (cognition, mental health and behaviour).



- 2.37** Considerable time and resources are needed to assess someone for CHC in accordance with the Framework's requirements, both in completing and documenting assessments of care needs and the DST. Health boards, in their responses to our survey, and some of the staff we met during our visits to three health boards, expressed concern about the capacity of health and social services practitioners to deliver the Framework.
- 2.38** The Framework stresses that the purpose of the DST is to help determine eligibility for CHC, and on its own it is not designed as a tool to assess care needs. Therefore, regardless of eligibility for CHC, a robust multidisciplinary assessment process is required to assess care needs. However, at our workshop, health board CHC leads told us that, contrary to the Framework's requirements, on occasions the DST is being used as a care needs assessment tool.
- 2.39** In their responses to our survey, all health boards stated that they encountered problems in getting the right people involved in the multidisciplinary DST completion process:
- a** all seven health boards referred to problems with getting GPs to attend DST meetings;
 - b** 10 out of the 16 local authorities who responded to our survey referred to difficulties in getting social workers involved, especially if this related to a case that was closed to social services;
 - c** three health boards highlighted a lack of consultant input; and
 - d** two health boards referred to occasional problems with getting therapists to attend DST meetings, due to their heavy workloads.
- 2.40** In each of the three health board areas we visited, social workers attended most multidisciplinary meetings to discuss and complete the DST. However, in some parts of Wales we found evidence of tensions between NHS and social services staff, with:
- a** two local authorities commenting on their survey returns that social workers are often the only non-health professional attending the multidisciplinary meetings, with the result that they can feel like a 'lone voice' and pressurised into agreeing a decision;
 - b** conversely, some NHS staff that we interviewed during fieldwork told us that they felt intimidated by social workers who were better versed in CHC case law; and
 - c** a number of local authorities within Betsi Cadwaladr University Health Board area told us that they are often given short notice of the multidisciplinary meetings and do not always receive copies of completed DSTs.
- 2.41** In two of the three health boards we visited the DSTs we reviewed were generally completed comprehensively, but in Betsi Cadwaladr University Health Board standards at that time were highly variable, and we found examples of:
- a** the DST being sketchily completed, with reference made to attached assessments and care plans that did not always read easily across to the domains of the DST;
 - b** sketchy completion of the local checklist that accompanies the DST, with responses to various prompts on key tasks, such as whether all professional assessments have been completed, not being supported by evidence; and

- c supporting documentation, such as needs assessments and risk assessments being completed after completion of the DST.

- 2.42** The Framework makes clear that whilst the DST should inform decision making, it should not directly determine eligibility – it should not just be a matter of ‘adding up the scores’ in the DST to see if someone is eligible. Indicative guidelines on eligibility are set out in the tool (for example, if one area of need is at priority level, then this demonstrates a primary health need), but the Framework states that professional judgement should be exercised in all cases to ensure that the individual’s overall level of need is correctly determined.
- 2.43** However, in their written submissions to us Crossroads, which provides support to carers, stated that in its experience the DST is often used too prescriptively, with an overreliance on ‘the scores’ within a DST and little professional judgement being used on whether the person meets the primary health need requirement. This view was shared by health board CHC leads and a number of health and social service practitioners we interviewed as part of our fieldwork. At our workshop, health board leads identified that multidisciplinary teams can lack confidence in decision making around CHC and, as a result, can place too much reliance on the tool.

Health boards have put in place scrutiny processes around CHC assessment and decision making, but their effectiveness varies

- 2.44** The multidisciplinary team makes the recommendation about eligibility for CHC, but the Framework makes clear that it is the health board which makes the final decision. All health boards have set up panels (known as scrutiny panels) to confirm the conclusions of multidisciplinary team assessments of eligibility for CHC, and to ensure the quality and consistency of decision making.
- 2.45** The number and scope of scrutiny panels varies between health boards, but it is common for a health board to have separate scrutiny panels for people with physical health needs, mental health needs and learning disabilities. There might be more than one scrutiny panel within a health board to cover physical health needs; for example, there might be separate panels for each local authority area within a health board. Also, there might be a single scrutiny panel, or separate panels, covering mental health needs and learning disabilities. Scrutiny panels consider recommendations for CHC, NHS-funded nursing care and the proposed care packages.
- 2.46** Health boards have put in place different arrangements to help ensure consistency between their scrutiny panels. In Aneurin Bevan Health Board, an overarching quality assurance panel ratifies all cases from the five locality-based scrutiny panels and the combined mental health and learning disability panel. In some other health boards, senior members of the dedicated CHC team attend all scrutiny panels.



- 2.47** The size and composition of scrutiny panels varies. Most scrutiny panels have between five and 10 members, including staff from the dedicated CHC team, operational management, and senior nursing staff, with representatives from social services attending in some health boards. Scrutiny panels should not have a financial gatekeeping function and, in line with the Framework's requirements, we found no evidence that finance officers are participating in scrutiny panels, although they can attend in an observer capacity.
- 2.48** Scrutiny panels should not complete or alter DSTs. Nor should they overturn recommendations. However, they can refer cases back to the multidisciplinary team for further work, for example where:
- a** the DST has not been fully completed;
 - b** there are significant gaps in the evidence provided to support the recommendation; or
 - c** there is an obvious 'mismatch' between the evidence provided and the recommendation made.
- 2.49** As part of our survey, we asked health boards to provide information on the proportion of cases being returned by scrutiny panels. The extent to which health boards could provide robust data was highly variable, and most were only able to provide broad estimates. These indicated considerable differences between health boards. The overall rates varied from seven per cent at Aneurin Bevan Health Board to 45 per cent in Abertawe Bro Morgannwg University Health Board. Three health boards were able to provide data by type of case. This showed that:
- a** at Abertawe Bro Morgannwg University Health Board the proportion of mental health cases returned by scrutiny panels at 90 per cent was far higher than for physical health cases (50 per cent) and learning disabilities cases (10 per cent);
 - b** in Betsi Cadwaladr University Health Board the proportion of mental health and learning disability cases returned, at 30 per cent, was also higher than for physical health cases (seven per cent); but
 - c** in Hywel Dda Health Board the proportion of mental health and learning disability cases returned, at six per cent, was below the average for all types of cases (nine per cent).
- 2.50** We explored some of the reasons for these variations during our fieldwork visits. In Aneurin Bevan Health Board, we found that cases are actively screened by members of the dedicated CHC team and returned to multidisciplinary teams prior to them being presented to a scrutiny panel. Although this adds a further step to the process, it allows for further information, if needed, to be requested at an earlier point and will have contributed to the low level of returns from scrutiny panels.
- 2.51** In Betsi Cadwaladr University Health Board, we found that in some mental health teams few nurses had attended the national CHC training course, which had resulted in a lack of understanding of CHC processes by the staff who are required to take a lead role in CHC assessments. In addition, our case file review found that for some mental health cases the DST was very sketchily completed, although there was far more detailed Care Programme Approach documentation. However, there is a poor fit between the domains of the DST and the eight key areas of life on which needs are assessed under the Care Programme

Approach. In these circumstances, it would not be easy for a scrutiny panel to assure itself that the evidence provided in Care Programme Approach documentation adequately supported a CHC eligibility recommendation. Both of these factors are likely to have contributed to the comparatively high rate of return of mental health cases in Betsi Cadwaladr University Health Board.

2.52 In their responses to our survey all health boards stated that, in line with the Framework, scrutiny panels do not reject or overturn multidisciplinary team decisions. We did find some evidence to suggest that health boards might not always be meeting the Framework's requirements in this regard:

- a** NHS and social services staff in Betsi Cadwaladr University Health Board area told us about recommendations on eligibility being changed before panel or overturned at panel; and
- b** three local authorities in their survey responses referred to the scrutiny process overturning decisions made in multidisciplinary team meetings.

2.53 However, in our discussions with health board CHC leads, it was suggested that these concerns most likely relate to cases which were referred back to the multidisciplinary team for further work (as permitted by the Framework), or to cases in which the eligibility decision was accepted but the proposed care package was amended (which is not covered by the Framework). Our case file reviews found no evidence of scrutiny panels rejecting or overturning decisions on eligibility.

2.54 In some parts of Wales, social services are actively involved in scrutiny panels. This was the case in two of the health boards that we visited, Hywel Dda and Aneurin Bevan, and both health and social services staff told us that this encouraged better joint working, clearer communication and an opportunity to resolve any issues in a timely manner. Both these areas experience relatively low numbers of disputes between health and social services over eligibility for CHC.

2.55 In Betsi Cadwaladr, the third health board area we visited, scrutiny panels do not include social services staff. Our fieldwork in Betsi Cadwaladr identified that communication between health and social services over eligibility decisions was often slow, and that some cases were 'bouncing back' between CHC scrutiny panels and social service panels for assessing eligibility for local authority services. This health board area also had a large number of disputes between health and social services over eligibility for CHC.

2.56 We also found that Betsi Cadwaladr University Health Board has separate scrutiny panels for low-cost and high-cost cases. The rationale for the separation was to ensure closer scrutiny of high-cost care packages, but in practice this also results in more senior staff scrutinising the eligibility decisions relating to high-cost cases. The high-cost panel has a broader and more senior membership, and the low-cost panel, which can be attended by as few as three staff, was acknowledged by health board managers at the time to provide less robust scrutiny than the high-cost panel. This practice appears to be contrary to the principles underpinning the Framework, as all cases should be dealt with consistently and financial considerations should not be a factor in the extent of scrutiny of CHC eligibility decisions.



2.57 Hywel Dda Health Board also has different arrangements, whereby for people with physical health needs each of the three localities has a scrutiny panel to ratify eligibility decisions and another panel to confirm the proposed care package or commissioning arrangements. These panels are held on the same day and the health board told us that separating consideration of the two issues was proving beneficial as it gives greater clarity and transparency over the decisions made as part of the scrutiny process.

Health boards do not measure the timescales for assessment and decision making, but the target times set out in the Framework are unlikely to be routinely met

2.58 The Framework stipulates two timescales relating to assessment and decision making:

- a** CHC assessment processes should be completed within six weeks of the ‘referral’; and
- b** it should take six to eight weeks from the date of ‘the initial trigger’ to agreeing a care package.

2.59 The Framework states that people who need an assessment of eligibility for CHC should be identified through the initial assessment undertaken by health and social service practitioners as part of the Unified Assessment Process. This contact assessment should, when appropriate, lead to a referral for full consideration of CHC eligibility. The Framework also refers to the referral being as the initial trigger for the CHC assessment process. However, health boards are unable to monitor performance against assessment time targets because the start point, the initial trigger or referral date, is not routinely recorded.

2.60 The health and social services staff we met as part of our fieldwork also wanted greater clarity over the start point against which timescales should be monitored. A contact assessment is not the only trigger for a CHC assessment, which could also be triggered as part of discharge planning in hospital or as part of a case review of someone in a care home. The use of the term ‘referral’ also causes some confusion, because a formal process for referring a person for a CHC assessment is not routine practice. Nor is it clear whether the start point should be the first time a professional identifies that a person needs to be assessed for CHC, or the point at which a person has regained maximum health and independence and is therefore ready for a CHC assessment. The adoption of a screening tool, which could be used by any relevant professional, would help provide a clearer and more consistent starting point for measuring timescales; in England a CHC eligibility decision is expected to take place within 28 days of the completion of the screening tool.

2.61 In their responses to our survey, only three health boards stated that they seek to monitor exceptions to the timescales prescribed in the Framework. However, in one of these, Aneurin Bevan Health Board, monitoring was on a case-by-case basis as part of the scrutiny process. It did not involve any overall analysis of cases, such as the average timescales being achieved, the proportion of cases meeting the prescribed timescales, or the range of timescales.

2.62 Our case file reviews in the three health boards we visited confirmed the difficulties health boards have in agreeing and recording a start point for monitoring assessment and decision-making timescales, and we were unable to establish the extent to which health boards are meeting the targets. However, based on our case file reviews, we concluded that health boards are unlikely to be routinely meeting target times, because:

- a** the time taken between the first assessment for CHC and confirmation of the multidisciplinary team's decision averaged between five weeks and nine weeks; and
- b** the average time taken to complete assessments across each of the three health boards hid significant variations between individual cases, with some taking four months or more to complete.

2.63 During our fieldwork, health board staff told us that there are a number of reasons why the target timescales may not be met. These included the limited availability of relevant professionals and family members to participate in assessments; the fluctuating condition of some individuals, necessitating additional assessments; and cases being returned to the multidisciplinary team by the scrutiny panel for further consideration or information.

Fast-track arrangements are generally working well

2.64 The Framework states that health boards should put in place a fast-track process for the immediate provision of CHC for individuals with a rapidly deteriorating condition who may be entering a terminal phase of their lives. The fast-track process should reduce the amount of information required, the time taken to gather information and the timescales for making a decision.

2.65 Most health and social services staff we interviewed considered that the arrangements for fast track were working well. At our workshop for health board CHC leads, when we asked about which elements of the Framework were working particularly well, there was a consensus that fast-track arrangements are a particular strength across Wales, and that the arrangements were being used appropriately by staff. An audit undertaken by Aneurin Bevan Health Board confirmed that its fast-track processes were being used appropriately. However, some social services staff we met during our fieldwork in other parts of Wales raised concerns over the timeliness of some fast-track assessments.



- 2.66** In response to our survey, four health boards stated that recommendations for urgent packages of care through the CHC fast-track process are routinely actioned immediately. However, three health boards stated that on occasions immediate action was not taken because, for example:
- a** the proposed urgent package of care was inappropriate for funding through CHC as it solely involved putting a meal in a microwave;
 - b** there was insufficient evidence provided to support the need for a fast track; and
 - c** Hywel Dda Health Board told us that on a few occasions the significant demand for home care packages and lack of capacity by NHS or independent services had led to a short delay in the provision of the care package.

2.67 The Framework states that before removing a package of care that was put in place through the fast-track process, the case should be reviewed in accordance with the normal review process. As part of their survey responses, all health boards indicated that they routinely complied with this requirement.

The transition from children services to adult services is highly problematic

2.68 The Framework outlines a number of arrangements that are required for planning for the transition from children to adult CHC services. In most health boards, the Framework's requirements in this regard are generally not being met (**Figure 9**), and the transition from children to adult services was seen by health board CHC leads as a significant weakness across Wales.

2.69 Our fieldwork visits identified that some children who meet the eligibility requirements for children CHC are, on their transition to adult services, deemed ineligible under the adult framework. It is difficult to see a rationale for someone becoming ineligible for CHC just because they reach a certain age whilst their needs remain the same. The impact of the *Children and Young People's Continuing Care Guidance*, published in November 2012, will need to be closely monitored in this regard.

2.70 The transition from children to adult services is a very complex area that can be difficult for professionals to navigate. There are differences between children services and adult services and between NHS and local authorities in terms of policies and processes, eligibility criteria, the age at which transition to adult services takes place, and the types of service available. Health and social service practitioners told us during our fieldwork that the Framework does not reflect the complexities of transition.

2.71 All three health boards we visited were taking steps to improve transition arrangements. Aneurin Bevan Health Board had established a transition group to identify problems and develop solutions, and intended to establish a transition panel to deal with individual transition cases. Betsi Cadwaladr University Health Board intended to fund a transition nurse. And, in one part of Hywel Dda Health Board, a pilot transition team was in place.

Figure 9 - Performance against the Framework's requirements for the transition from children to adult services

Framework requirement	Performance
<p>Adult CHC should be appropriately represented at all transition planning meetings to do with individual young people whose needs suggest they may potentially become eligible for adult CHC (Framework paragraph 9.8).</p>	<p>In response to our survey, all health boards stated that they had experienced problems with this 'some of the time'.</p>
<p>Local authorities and LHBs should have systems in place to ensure that appropriate referrals are made whenever either organisation is supporting a young person who, on reaching adulthood, may have a need for services from the other organisation (9.8).</p>	<p>In their responses to our surveys, only two health boards and five out of 16 local authorities stated that they always achieved this.</p>
<p>Planning should commence when the child is aged 14 (9.10).</p>	<p>No health board stated that this 'always' occurred; one health board stated that this occurred 'most of the time'; four stated this occurred 'some of the time'; and two stated that this does not routinely occur. During our case file reviews, we found little evidence of planning commencing when the child reaches the age of 14.</p>
<p>At the age of 17, eligibility for adult CHC should be determined in principle so that, wherever applicable, effective packages of care can be commissioned in time for the individual's 18th birthday (or later, if it is agreed that it is more appropriate for responsibility to be transferred then) (9.10).</p>	<p>No health board stated that this 'always' occurs; four stated that this occurs 'most of the time'; one health board stated this occurs 'some of the time', and one health board stated that this does not happen routinely (one health board did not respond to this question).</p> <p>Our case file reviews showed variable performance, with some well-planned cases but also some cases where decisions had not been made when the person had reached 18 years of age.</p>
<p>A consistent package of support should be provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of the move from children to adult services or because of a switch in the organisation with commissioning or funding responsibilities (9.13).</p>	<p>Only one health board and no local authority stated that it was 'always' normal practice to maintain a consistent package of care during the transition to adulthood. One health board and five local authorities stated that it is not normal practice. The remainder indicated that this was either the case 'most' or 'some of the time'.</p>

Source: Wales Audit Office surveys of health boards and local authority social services departments October 2011, and case file reviews December 2011 to January 2012



Arrangements for reviewing continuing eligibility for CHC have been strengthened, but cases are not always being reviewed as frequently or as robustly as required by the Framework

CHC cases are not being reviewed in accordance with the requirements of the Framework but, since the introduction of the Framework, health boards have made some progress in dealing with backlogs of reviews

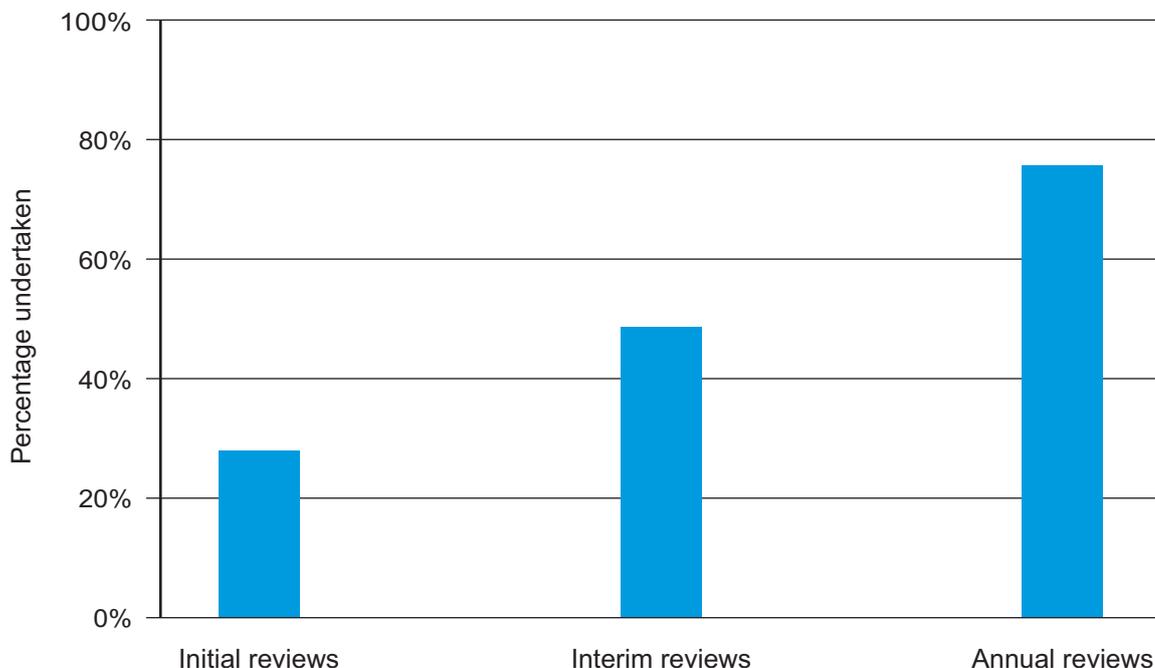
2.72 The Framework anticipates some people moving into and out of CHC eligibility, as their health care needs change over time, and an individual's continuing eligibility for CHC is subject to periodic review. The Framework states that, as a minimum, there should be an initial review of CHC cases within six weeks and an interim review after three months of the services being provided. Thereafter, reviews should be at least annually. The outcome of a review should be a determination of whether an individual's needs have changed, which should then determine whether the package of care needs to be revised and whether the person continues to be eligible for CHC funding.

2.73 Routine and comprehensive information on the extent and frequency of reviews carried out is not currently available across all parts of Wales. However, the roll out of the national CHC database should allow health boards to monitor their performance against the Framework's requirements in the future. As part of our case file reviews in the three health board areas we visited, we examined the extent to which reviews have taken place as specified by the Framework. We looked at whether initial, interim and annual reviews were carried out, and, if so, whether they were carried out at the times prescribed by the Framework.

2.74 In terms of whether reviews are carried out, we found that for a substantial number of cases the Framework's requirements for undertaking initial, interim and annual reviews are not being met (**Figure 10**).

2.75 The percentage of cases with an interim and annual review was similar across all three health boards, although the reviews were not always undertaken within the prescribed timescales. However, the percentage of initial reviews carried out varied from just 16 per cent at Aneurin Bevan Health Board and 17 per cent at Betsi Cadwaladr University Health Board to 40 per cent at Hywel Dda Health Board. The capacity to undertake reviews was an issue raised by staff at all three health boards we visited. Staff at Aneurin Bevan Health Board told us that the Framework's requirements for reviews are impractical given the existing level of resources. As a result, the health board does not seek to undertake initial reviews of all cases, but instead looks to target what it considers to be the most appropriate cases. The requirements for review are less onerous in England, where the first review should take place no later than three months after the initial eligibility decision, and then at least once a year subsequently.

Figure 10 - Percentage of initial, interim and annual reviews undertaken across the three health boards visited



Note

Annual reviews cover both pre- and post-Framework cases

Source: Wales Audit Office case file reviews undertaken between November 2011 and January 2012

2.76 In response to our survey, all health boards confirmed that they were working towards reviewing CHC cases that pre-dated the Framework on an annual basis, but given the volumes concerned, not all cases had yet been reviewed. Our case file analysis across three health boards during December 2011 and January 2012 established that 87 per cent of pre-Framework cases had

been reviewed since August 2010. We also examined whether annual reviews were being undertaken on cases that became eligible for CHC after the Framework had been implemented. Only a small number of the cases we examined had been due an annual review, and just 45 per cent of these cases had been reviewed.



2.77 We found that the timing of initial reviews, when undertaken, varied, but were generally carried out around the six-to-eight-week point, broadly in line with the prescribed timescales. However, where interim reviews were carried out, they often did not take place to the timescales prescribed by the Framework. Although one in two cases across the three health boards had an interim review, the reviews were more likely to occur around the six-month point rather than the prescribed three months. For annual reviews of cases approved before the implementation of the Framework, all three health boards we visited had made efforts to catch up on previous review backlogs, with some cases not having been reviewed previously for a number of years. Insufficient time has elapsed to fully assess the timing of annual reviews for post-Framework cases.

The robustness of reviews is highly variable, with a reluctance to move people out of CHC evident in some parts of Wales

2.78 The Framework states that reviews should follow the format of an assessment, consider all of the services received and be tailored to the individual. The Framework sets out a number of requirements for health boards and their partners to meet in undertaking reviews, but responses to our survey of health boards indicated that the requirements are not being universally met (Figure 11). Our case file reviews and fieldwork interviews at the three health boards we visited also identified that practices vary considerably, with:

- a** the rate of movement of people out of CHC following review being far more frequent in some health boards than in others;
- b** a reluctance by nursing staff to consider moving people out of CHC in one area we visited; and
- c** different approaches to the review of pre-Framework cases that might not have been accepted for CHC under the Framework criteria – some health boards only review eligibility if there is a clear change of need, whilst others will review the original decision even if needs have not changed.

Figure 11 - Performance against the Framework requirements for CHC reviews

Framework requirement	Performance
<p>Reviews should follow the format of an assessment and use the DST (Framework paragraphs 8.1 and 5.25).</p>	<p>In response to our survey, all health boards stated that reviews follow the format of an assessment, but to varying degrees:</p> <ul style="list-style-type: none"> • three health boards stating this is 'always' the case; • three health boards stating that this is the case 'most of the time'; and • one health board stating that this is the case 'some of the time'. <p>Our case file reviews identified differing practices in the use of the DST as part of the review process across the three health boards visited. In Hywel Dda and Betsi Cadwaladr University Health Boards, reviews are based on nursing assessments only, with no evidence that assessments against each of the DST domains were reconsidered. Within mental health services in all three health boards, Care Programme Approach documentation tends to be used with no clear link to the DST domains.</p>
<p>It is beneficial for social services to be involved in reviews (8.5).</p>	<p>Two-thirds of responding local authorities said that they had difficulties ensuring that social services staff attend all CHC review meetings, largely due to competing demands upon their time. Two authorities stated that they now only send a social worker to a CHC review meeting if there is a threat of CHC funding being withdrawn. Generally, our case file reviews found little evidence of social worker input to reviews.</p>
<p>Prior to the review, individuals should be offered the opportunity to reassess their own needs and be offered appropriate support to do so (8.4).</p>	<p>In their responses to our survey, no health board stated that this was 'always the case'; two health boards stated this occurred 'most of the time'; one stated that this happened 'some of the time'; three stated that this was 'not normal practice'; and one stated that practices varied across the health board area.</p>
<p>A joint reassessment of the individual by the health board and local authority should take place prior to a withdrawal of CHC funding (8.15).</p>	<p>All health boards stated that this was always the case, but seven of the responding 17 local authorities reported that they were aware of occasions when CHC funding had been withdrawn without a joint reassessment taking place.</p>

Source: Wales Audit Office surveys of health boards and Social Services October 2011, and case file reviews December 2011 to January 2012

2.79 The Framework does not explicitly state how health boards should oversee and confirm any change in eligibility following a review. However, across the three health boards we visited, scrutiny panels reviewed all cases in which there had been a proposed change in eligibility.



The effectiveness of joint working between health and social services is highly variable

There are significant variations in joint working arrangements between health and social care

2.80 The importance of joint working between the NHS and social services is stressed throughout the Framework. In our survey, we asked local authorities what they considered to have been the main successes in implementing the Framework and five of the 18 responses highlighted the improvements to joint working that had resulted from the Framework. At our workshop, CHC health board leads confirmed that improved joint working with local authority partners was one of the benefits that the Framework has delivered in some parts of Wales.

2.81 However, the responses to our surveys and discussions at the workshop of CHC health board leads also indicated that the extent and effectiveness of joint working between social services and health is highly variable. We also identified significant differences in the extent and effectiveness of joint working in the CHC assessment and review processes between and within the three health board areas that we visited. We found that:

- a** the extent of engagement of social services in health boards' scrutiny panels varied;
- b** the approaches of health boards in engaging social services in the development of local CHC operational policies varied, from consulting local authorities on policies through to formally agreeing policies with all partners;

- c** all three health boards had developed, or were developing, in conjunction with social services specific joint protocols, most notably in Aneurin Bevan Health Board where joint protocols have been developed for dispute procedures, fast-track processes and care home closures;
- d** Betsi Cadwaladr University Health Board was experiencing difficulties in agreeing a common approach with the six local authorities in its area;
- e** some joint health and social services posts had been established, most notably within the Hywel Dda Health Board area, at county director, heads of service and locality manager level; and
- f** in Betsi Cadwaladr University Health Board area, a lack of permanent staff appointments following reorganisation within the NHS was undermining joint working.

2.82 In two of the three health board areas we visited, Aneurin Bevan and Hywel Dda, senior health board and social services staff told us that they had positive and constructive joint working relationships. Relationships were far more variable across the Betsi Cadwaladr University Health Board area, and health and social services managers described relationships between the health board and Conwy and Denbighshire local authorities at that time as 'difficult'. At an operational level, the quality of working relationships was variable across all the three health boards we visited, and our interviews with health and social services staff revealed varying degrees of tension, conflict and trust.

2.83 The Framework highlights the importance of health boards contracting for services, such as care home placements, jointly with local authority partners. A number of initiatives are supporting the development of joint commissioning and contracting. These include a commitment in Sustainable Social Services²⁵ for local government to work with their NHS partners to develop a single approach across Wales; and the CHC programme board identifying this as a work stream in 2011-12.

2.84 However, there has been limited progress on the ground in developing joint commissioning and contracting arrangements for care home placements. Our fieldwork and our workshop for health board CHC leads identified examples of commissioning initiatives being undertaken within the NHS or within and between local authorities, but we did not find any examples of health boards and local authorities commissioning jointly. As a result, opportunities for improving value for money may have been missed. In addition:

- a** local authorities told us during our fieldwork visits that the differing contracting arrangements between the NHS and social care can undermine the consistency of care – for example, it can be appropriate for people experiencing a change in who funds their care (NHS or local authority) to remain in the same care home, but they may have to move because of the contracts each organisation has in place; and
- b** there can be a disincentive for care homes to provide places for people in receipt of CHC – NHS and local authority staff told us of examples where the combined fees paid to a care home by the local authority and the NHS contribution for NHS-funded

nursing care exceeded the rate being paid for a CHC placement, resulting in the care home providing more intensive or complex care for a CHC placement for a lower fee.

The number of disputes between health and social services varied and, although relevant policies and guidance are mostly in place, the time taken to resolve disputes is significantly longer than the target times set out in the Framework

2.85 The number of disputes between health and social services over CHC eligibility decisions in the health board areas we visited varied. Aneurin Bevan Health Board has had only one dispute since the Framework was introduced and this related to a cross-border issue. Although Hywel Dda Health Board had had just two disputes since the Framework was introduced, one of the local authorities reported that a number of potential disputes were in the pipeline. In Betsi Cadwaladr University Health Board, disputes were common, especially with Conwy County Borough Council where:

- a** an inter-agency dispute procedure had not been formally agreed;
- b** there was a distinct lack of trust between health and social services staff, with a confrontational approach, involving solicitors, evident;
- c** differences at a multidisciplinary team level were quickly escalated to a formal dispute stage;
- d** the local authority told us that communication from the health board was poor, there was a lack of clarity over who to contact within the health board, and response times were slow; and

²⁵ Sustainable Social Services for Wales: A Framework for Action, Welsh Government, 2011



- e the extent of the problems necessitated setting up a joint working task and finish group.

2.86 The Framework outlines a number of requirements in relation to handling disputes between health boards and social services departments. The responses to our surveys indicate that the extent to which the Framework’s requirements are being met varies across Wales (Figure 12).

Figure 12 - Performance against the Framework’s requirements in respect of disputes between organisations about CHC eligibility and funding

Framework requirement	Performance
Health boards and local authorities should have in place locally agreed procedures or protocols for dealing with any disputes about eligibility for CHC (Framework paragraph 11.1).	At the time of our review of documentation from all health boards, Abertawe Bro Morgannwg and Cwm Taf did not have a separate policy or detailed local arrangements in their overarching CHC policy for dealing with disputes between agencies over eligibility for CHC.
Health boards and local authorities should have in place locally agreed procedures or protocols for dealing with any disputes about the apportionment of funding in jointly funded care packages (11.1).	In their responses to our survey, two of the seven health boards, Abertawe Bro Morgannwg and Powys, stated that they did not have a protocol with local authorities in place for resolving disputes over the apportionment of funding in jointly funded care packages.
Current CHC funding should not be withdrawn prior to the dispute being resolved (11.2).	Three of 17 responding local authorities stated that they were aware of occasions when the current CHC funding had been withdrawn prior to a dispute being resolved.
All stages of disputes procedures will normally be completed within two weeks (11.4).	Six of the seven health boards and all 13 responding local authorities stated that all the stages of dispute procedures were not normally completed within two weeks. Survey responses identified that typically it can take a number of months to resolve a dispute, sometimes more than a year. The reasons given by health boards and social services departments as to why the Framework timescales were not being achieved included the complexity of the cases, and the time taken to gather additional information and medical evidence.

There is mixed evidence on the extent to which individuals and their families are being involved in the assessment process, and processes for gaining and recording informed consent and assessing mental capacity are very inconsistent

There is scope to improve the information on CHC that is made available to the public

2.87 CHC is a complex topic with its own distinct language, and ensuring people are well informed is a particular challenge. The Framework states that the person who is undergoing a CHC assessment and their family and/or carers should understand the process, and receive advice and information in a timely manner to enable them to participate in informed decisions about future care.

2.88 The Welsh Government developed a bilingual information leaflet for health boards to issue to people being assessed for, or in receipt of, CHC and their carers. The Welsh Government, with the support of Age Concern, has developed a more detailed guide on the CHC assessment process for the public. However, our fieldwork and survey responses identified that:

- a** inadequate stocks of the information leaflet have been maintained and some health boards had run out of supplies;

- b** some health staff were not routinely issuing the information leaflet to people being assessed for CHC and their carers;
- c** some health boards did not have the leaflet available in braille, minority languages and audio; and
- d** health boards do not issue copies of the detailed guide, although the guide can be found on their websites.

2.89 In their survey responses, health boards identified some gaps in the standard information that is made available. They considered that more public information is needed with regard to consent and capacity; joint care packages; the national CHC sustainability policy on care planning²⁶; and the availability of local advocacy support. One health board suggested that the use of examples of cases that met CHC eligibility criteria would help improve the public's understanding of CHC.

2.90 In their written submissions to us, some organisations providing support and advocacy to people being assessed for CHC, such as Age Cymru, reported very mixed experiences around how well people are kept informed about CHC assessment and decision-making processes. Experiences ranged from every meeting being 'clear and easy to understand' with things 'always well explained', through to 'the whole process being deliberately designed to be complex and hard for the public to understand' with the effect that 'the family throws the towel in'.

²⁶ A Sustainable Care Planning in Continuing NHS Healthcare operational policy was agreed by all health boards in 2011 which outlines the key factors that will be considered when developing care packages following an eligibility decision; these cover sufficiency, safety, quality, reliability and affordability.



The Framework confirms the requirement to obtain the informed consent of people being assessed for CHC, but the practice in obtaining and recording consent varies across Wales

- 2.91** The Framework states that an individual's informed consent should be obtained and documented before the process of determining eligibility for CHC begins and before any decisions are made. Unlike in England, the Framework does not make explicit the need for consent for sharing information between organisations, as well as for assessments, to be obtained from individuals.
- 2.92** The Framework in Wales stipulates that each professional involved, such as nurses, doctors and social workers, should each seek consent to conduct their individual assessments. The Framework in England is less onerous and does not expect that each professional obtains consent, rather that: 'it should be made explicit to the individual whether their consent is being sought for a specific aspect of the eligibility consideration process (eg, completion of the Checklist) or for the full process'.
- 2.93** Some health board and local authority staff told us during our fieldwork that the Framework has improved clarity over the requirements to obtain consent and the capacity of individuals to provide it. However, we found inconsistent practices relating to consent within and between health boards. For example:
- a** some health boards lack locally agreed protocols on the processes to be followed if there is a refusal of consent to a CHC assessment – in their responses to our survey, only four health boards stated that they had such a protocol, although one health board's protocol had not been agreed with its local authority partners;
 - b** the proportion of health staff involved in assessing patients that health boards estimate to have been trained in the process of obtaining consent was highly variable – with three health boards estimating this to be between 26 per cent and 50 per cent, one estimating this to be between 51 per cent and 75 per cent, and two estimating this to be between 76 per cent and 100 per cent (one health board did not respond to this question);
 - c** consent is not being gained for all individual specialist assessments – the evidence of consent we found in the case files we reviewed related to a single consent form rather than consent for each individual assessment;
 - d** the standard of consent forms varied across Wales – in Aneurin Bevan Health Board area the consent form in use related to sharing information, rather than being assessed for CHC, whereas Betsi Cadwaladr University Health Board had a comprehensive consent for assessment form; and
 - e** we frequently found a lack of evidence on case files that consent had been granted – where documentation included a prompt to indicate consent, it was often not completed and signed by the individual.
- 2.94** Entitlement to social security and other welfare benefits, such as the Independent Living Fund, that are available to support someone's living costs, may be affected by eligibility for CHC. Informed consent cannot properly be given unless an individual understands the potential impact of CHC on his or her benefits or allowances. As a result, the Framework states that the impact of CHC eligibility on benefit entitlements must be discussed with the person being assessed.

2.95 It is the role of social services to ensure that individuals are fully informed of the benefit implications of claiming CHC. However, it is important that NHS staff have a basic understanding of how benefits and allowances could be affected by CHC to allow them to effectively direct the person being assessed to social services. Some basic training on benefits and allowances is included in the initial training day on CHC that is run across Wales. However, from our case file reviews and interviews with nursing staff at the three health boards we visited, we found:

- a** that many nurses did not consider it to be part of their role to provide advice on benefits, and did not feel well equipped to do so; and
- b** little evidence that the potential impact of CHC on benefits or allowances had been discussed with people being assessed by either health or social services staff.

Health boards are inconsistent in the extent to which they routinely assess the mental capacity of people being assessed for CHC to give their consent and participate in decision-making processes

2.96 Most patients who are likely to be offered a CHC assessment have significant health care needs. Their ability to provide their consent to the CHC process can often be impaired by their mental capacity or physical ill health that affects their ability to communicate their consent. The Framework states that:

- a** if there is a concern that an individual may not have the mental capacity to give their consent or to participate effectively in the decision-making process, consent should be determined in accordance with the Mental Capacity Act 2005 and the associated code of practice; and

- b** if an individual lacks the mental capacity either to consent to or refuse an assessment, a 'best interests' decision should be taken, and documented, as to whether or not to proceed with the assessment of eligibility for CHC.

2.97 The evidence from our case file reviews suggests that the extent to which mental capacity is considered as part of the assessment process varied across the three health boards. We looked for evidence that standard documentation prompted the consideration of mental capacity, that mental capacity had been considered and that, where appropriate, copies of 'best interest' forms were placed on the case files. We concluded that robust arrangements for assessing mental capacity operated in Aneurin Bevan Health Board, the effectiveness of the arrangements across Betsi Cadwaladr University Health Board varied, and in Hywel Dda Health Board there was little evidence to suggest that the mental capacity of people being assessed for CHC was being routinely considered by operational staff.

There is mixed evidence on the extent to which individuals and their families are being involved in the assessment process

2.98 The Framework encourages the active involvement of individuals and their families or carers during all stages of their assessment for CHC and the planning of their care. At our workshop, CHC health board leads told us that the Framework had increased the focus on involving individuals and their families or carers in the CHC assessment process. However, responses to our survey of health boards indicated that the Framework's requirements for involving individuals and their families were not always being met (Figure 13).



Figure 13 - Performance against the Framework's requirements in respect of disputes between organisations about CHC eligibility and funding

Framework requirement	Performance
Individuals should always be given the opportunity to participate in the completion of the DST (Framework paragraph 5.28).	In their responses to our survey, two health boards stated that people being assessed were 'always' given the opportunity to participate in the completion of the DST, with the remainder stating this occurred 'most of the time'.
Individuals should always be given the opportunity to be supported or represented by a carer or advocate as part of the completion of the DST (5.28).	Four health boards stated that individuals are always given the opportunity to be supported or represented by a carer or advocate as part of the completion of the DST, with the remainder stating this occurred 'most of the time'.
Review timescales should be communicated in writing to the individual and their relatives (8.3).	One health board stated that it does not communicate review timescales in writing to the individual and their relatives, with a further two stating that this occurred 'some of the time'.
Individuals should be offered the opportunity to reassess their own needs prior to a review (8.4).	Three health boards stated that it was not normal practice to offer patients the opportunity to reassess their own needs prior to a review, with a further health board stating that that it was normal practice 'some of the time'.

2.99 From our case file reviews, we found that the files in support of the DST in Aneurin Bevan and Betsi Cadwaladr University Health Boards consistently recorded the views of individuals and/or their families. However, in Hywel Dda Health Board the evidence was less conclusive.

2.100 During our fieldwork visits, some health and social care practitioners told us that the Framework requirement that the individual and his or her family should be invited to the DST meeting was an appropriate way to involve people in the assessment for CHC. However, some practitioners raised concerns about the length of DST meetings, which can often last for longer than three hours, the technical language and jargon used in the meetings, and the stress that attendance at DST

meetings can create for the individual or family member. These practitioners considered that there are better ways to involve people. For example, in some of the case files we examined, we found clearly documented notes of meetings between nurses and the individual and family members that had taken place both before and after the DST meeting.

2.101 In their written submissions to us, organisations that provide advocacy services have stated that individuals and their carers have had very mixed experiences about the extent to which they have been involved in CHC processes. Experiences ranged from 'always been given an opportunity to speak at any point during a meeting' through to 'being ignored, intimidated and made to feel stupid'.

2.102 Both Age Concern and the Older People's Commissioner for Wales expressed concerns over communications between health board staff and patients and their families. For example, the Older People's Commissioner for Wales questioned the extent to which older people are well informed about CHC and how proactive professional staff are in helping people understand CHC. She also pointed to a lack of routine communication with patients and their relatives on progress and the next steps in the process.

There is evidence to suggest that in some areas, the needs of carers are not being fully assessed

2.103 The Framework's requirements relating to carers' assessments are not being consistently met across Wales (Figure 14). Our case file reviews found that in Aneurin Bevan Health Board, carers' assessments were regularly offered and recorded within case files. In the other two health board areas we visited, we found little evidence from case files that carers' assessments were being offered. However, interviews with health and social service practitioners in these health board areas pointed to carers' assessments being carried out routinely by social services staff.

Figure 14 - Performance against the Framework's requirements in respect of carers' assessments

Framework requirement	Performance
Where informal carers are being asked, or are offering, to provide substantial care on a regular basis, they have a right to have their needs as a carer assessed; health boards and local authorities must inform carers of this right (Framework paragraph 6.23).	In their responses to our survey, only one health board stated that carers were 'always' informed of their right to a carer's assessment, with a further health board stating that this occurred 'most of the time'. Four health boards stated that this occurred 'some of the time', and one stated they 'did not know' how frequently this was occurring.
A further carer's assessment should be considered at the time of a review (8.4).	Only one health board stated that staff routinely consider whether a further carer's assessment should be undertaken at the time of a review; two health boards stated this happens 'most of the time', with three stating that this happens 'some of the time'; and one health board stated this was not routine practice.



Part 3 - There is a significant risk that the national project to deal with retrospective claims for CHC will not process all cases by the agreed deadline, and new backlogs of retrospective claims have developed in health boards

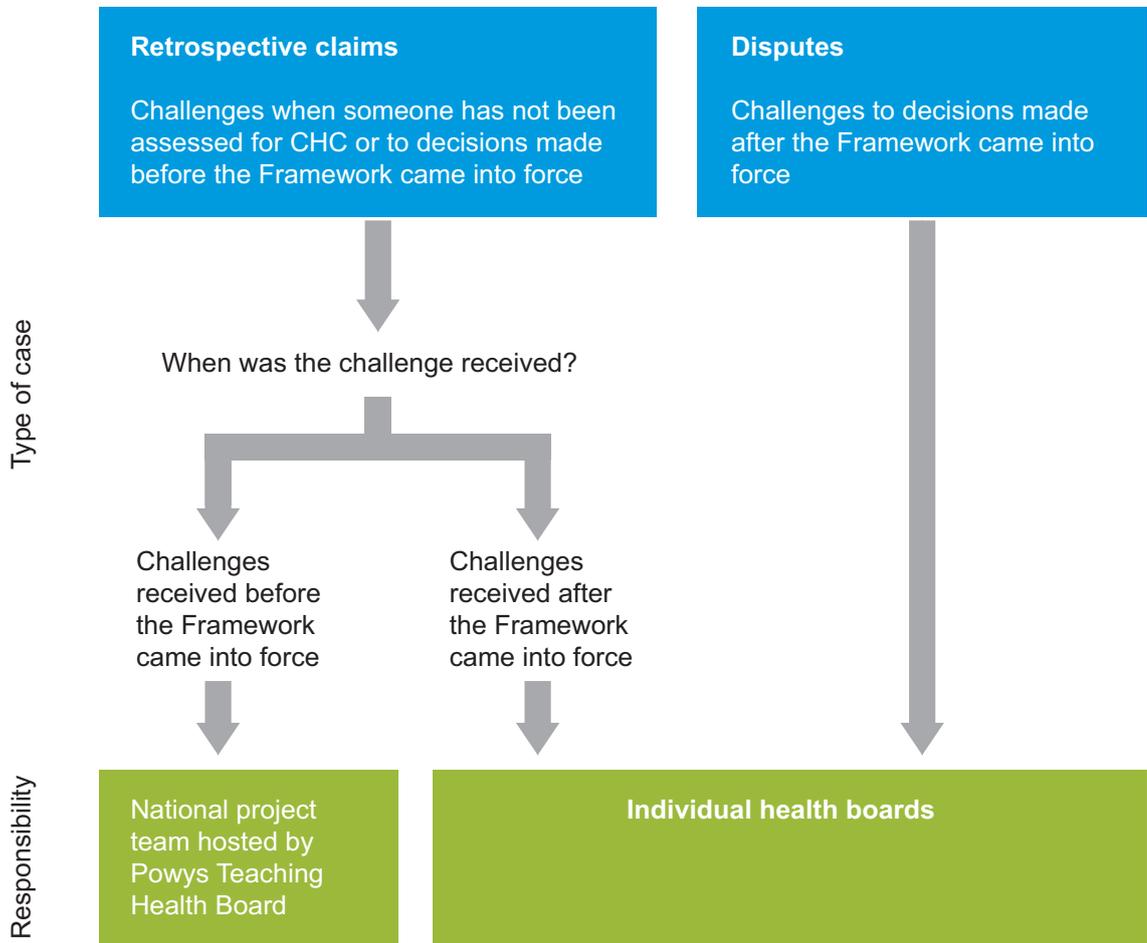
Many of the challenges around CHC eligibility have not been dealt with promptly, and although there is a longstanding deadline for clearing the cases being dealt with by a national project team, no deadline has been set for the cases that health boards are dealing with

Responsibility for dealing with retrospective CHC claims is either with a national project team or with individual health boards depending upon the date of the claim

- 3.1** There are two types of situation in which someone or their family can challenge health boards over their eligibility for CHC:
- a** retrospective claims – these relate to cases where someone was not previously assessed for CHC or where, prior to the introduction of the Framework in August 2010, an assessment resulted in an ineligibility decision; and
 - b** disputes – these relate to cases where an individual or their family request the health board to reconsider an eligibility decision made after August 2010.

- 3.2** Successful challenges result in the reimbursement of the care home fees paid by the individual, plus interest. The responsibility for processing these cases has changed over time, but currently rests either with a national project team hosted by Powys Teaching Health Board or with individual health boards (Figure 15). Responsibility for any financial reimbursement rests with the originating health board.

Figure 15 - Responsibility for handling retrospective claims and disputes





National arrangements were originally set up to deal with retrospective claims relating to cases up to 2003, and the subsequent setting of a deadline for claims to be submitted led to a big increase in the number of cases

- 3.3** In February 2003, the Health Service Ombudsman found that a number of people had been wrongly charged for elements of their care when they should have been treated as eligible for CHC and all their care provided free by the NHS.²⁷ The ombudsman recommended that efforts should be made to remedy any financial injustice to patients where the CHC criteria, or the way they were applied, were not clearly appropriate or fair. The recommendation was accepted in Wales and in England.
- 3.4** In 2004²⁸, arrangements were established with what is now Powys Teaching Health Board, which allowed people to claim retrospectively that they (or their deceased relative) had been eligible for CHC but were wrongly charged for care between 1996 and 2003. Claims for periods subsequent to 2003 were to be processed by the local health board where the claimant lived.
- 3.5** Following an announcement by the Welsh Government in July 2009 that no new retrospective claims relating to the period up to April 2003 would be considered if received after 4 December 2009, there was a considerable influx of new claims. Following the announcement, around 3,500 potential new retrospective claims were received by 4 December 2009. Claimants were given until 17 May 2010 to provide the required legal entitlement to pursue a claim and proof that they had paid care home fees during the claim period. A total of 2,485 claims were validated

to move forward, with a further 418 possible claims pending with mitigation for not meeting the May deadline.

In June 2011, the national arrangements were revised to cover all retrospective claims up to August 2010, and a deadline set to clear all these cases by June 2014

- 3.6** The arrangements for dealing with retrospective claims were amended in June 2011²⁹, and Powys Teaching Health Board's responsibility was extended to cover all retrospective claims relating to periods up to 15 August 2010, the Framework's implementation date. To limit the numbers of cases being dealt with by the Powys project, the arrangements were subsequently changed in September 2011 to include only those cases where a claim had been received before 15 August 2010.
- 3.7** Although the Public Services Ombudsman for Wales was critical that a large number of retrospective cases had been allowed to build up, he accepted that the Welsh Government's proposals to tackle the backlog were reasonable. The Welsh Government subsequently confirmed in 2011 that all claims submitted before 15 August 2010 should be cleared within a three-year timeframe and set a deadline to clear all cases by June 2014.
- 3.8** The arrangements within the Powys project for dealing with individual cases were revised in June 2011, with the aim of having a robust assessment process in place that leads to a decision as quickly as possible. A performance management group was also established to direct and oversee the national project. The group is chaired by the project lead director and includes representatives from health boards and the Welsh Government.

²⁷ NHS funding for long term care, Health Service Ombudsman, February 2003

²⁸ Welsh Health Circular (2004) 54

²⁹ Welsh Government Circular 13/2011

- 3.9** The assessment process has one of three potential outcomes:
- a** matching – eligibility for the full period of the claim is agreed by project staff;
 - b** negotiation – discussions are held between the project staff and the claimant and result in all parties agreeing eligibility for part of the claim period, or agreeing that the case was not eligible for CHC; or
 - c** panel hearings – for complex cases where it is difficult to determine eligibility, or where cases have not been resolved by negotiation, a panel makes a final decision on the case.
- 3.10** The panel consists of an independent chair; a clinician with a background in the claimant's health condition; a senior clinician with knowledge of CHC, who is from a health board in Wales but not associated with the health board who provided care to the claimant; and a representative of a local authority that, where possible, is not associated with providing care to the claimant.

Health boards have been confused about their responsibilities for retrospective claims, and the timescales for dealing with retrospective claims and disputes are unclear

- 3.11** The Welsh Government did not formally communicate to health boards its decision in September 2011 to change the criteria, from the claim period to the date the claim was made, for determining whether the Powys project or individual health boards are responsible for dealing with retrospective claims. The Welsh Government did confirm the change to health board CHC leads who attended the National CHC Implementation Group meeting in September 2011, but the CHC leads for two health boards did not attend this meeting.

- 3.12** Whilst June 2014 has been set as a deadline for the clearing of retrospective claims being processed by the Powys project, the Welsh Government has not set a timetable for clearing the retrospective claims that are being managed by health boards. The Welsh Government told us that it intends to consider the timescales associated with the clearance of claims by health boards as part of its forthcoming review of the Framework.
- 3.13** In addition to dealing with retrospective claims, health boards are also responsible for handling disputes over decisions made after the implementation of the Framework. An individual may apply to the health board for an independent review of a decision on eligibility for CHC if he or she is dissatisfied with the:
- a** procedure followed in reaching a decision on eligibility for CHC; and/or
 - b** application of the primary health need consideration.
- 3.14** The Framework outlines a number of requirements for health boards to meet in dealing with disputes. Health boards should first seek to resolve any disputes informally before they refer the case to an independent review panel. However, other than stating that NHS organisations should deal promptly with any request to reconsider decisions about eligibility for CHC, the Framework does not include standards or guidelines for the maximum time it should take to resolve a dispute.

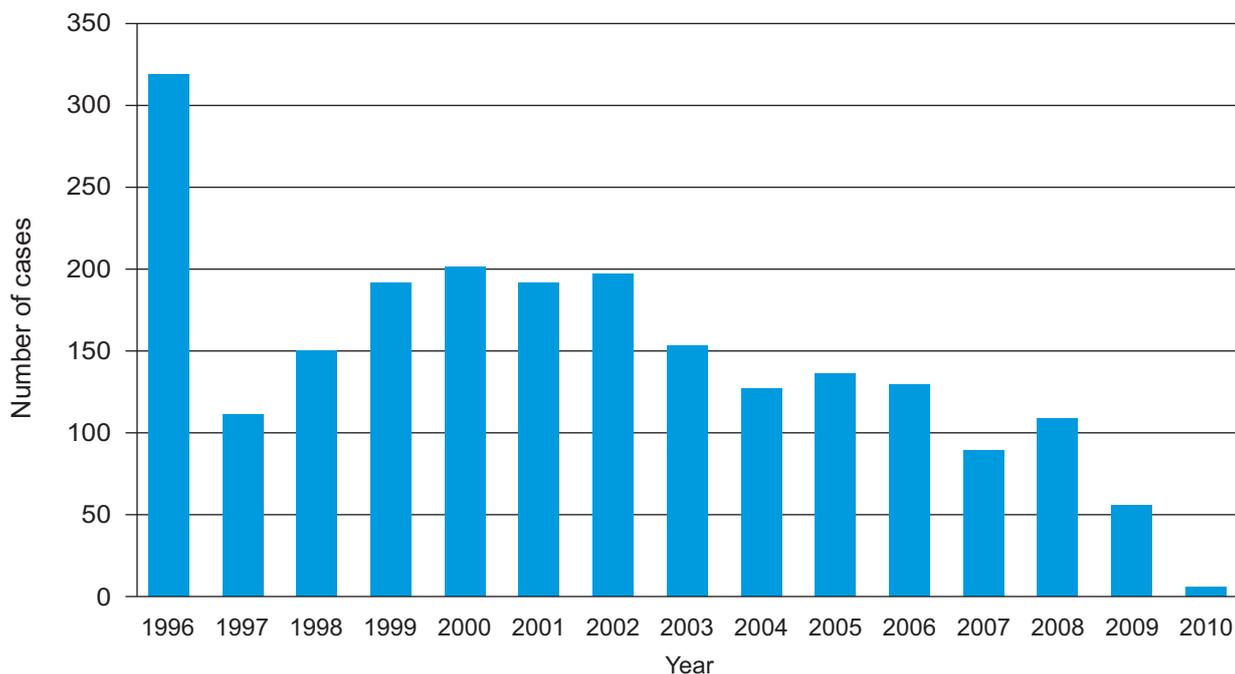


A failure to deal promptly with retrospective claims and disputes is unfair on the individuals concerned

3.15 As at May 2012, the retrospective claims being dealt with by the Powys project, but which had not been resolved, related to periods dating back up to 17 years (Figure 16). The claim periods involved can also cover many years, with the longest claim period at that time being more than 14 years. Given the timescales involved, more than four in every five cases are being pursued by family members on behalf of a relative who has died.

3.16 The claimant bears the cost of any care fees whilst a retrospective claim or dispute is outstanding, but if successful the claimant is reimbursed the relevant fees. As a result, delays can lead to financial hardship and distress for successful claimants up until the time that the claim or dispute is resolved. For example, the Alzheimer’s Society told us of one case where a person with dementia was moved from the care home they were in, away from a familiar environment and to the detriment of their health, as the family could not afford the cost of the care home while the case was being reconsidered.

Figure 16 - Powys project retrospective cases – year in which claim period commences



Source: Wales Audit Office analysis of retrospective claims database as at May 2012

The national project for dealing with retrospective claims has made limited progress and, despite additional funding and reassurances from Powys Teaching Health Board that the June 2014 deadline to clear all claims will be met, in our view there remains a significant risk that the deadline to clear all claims by June 2014 will not be achieved

Progress has been limited and a significant number of cases remain to be processed

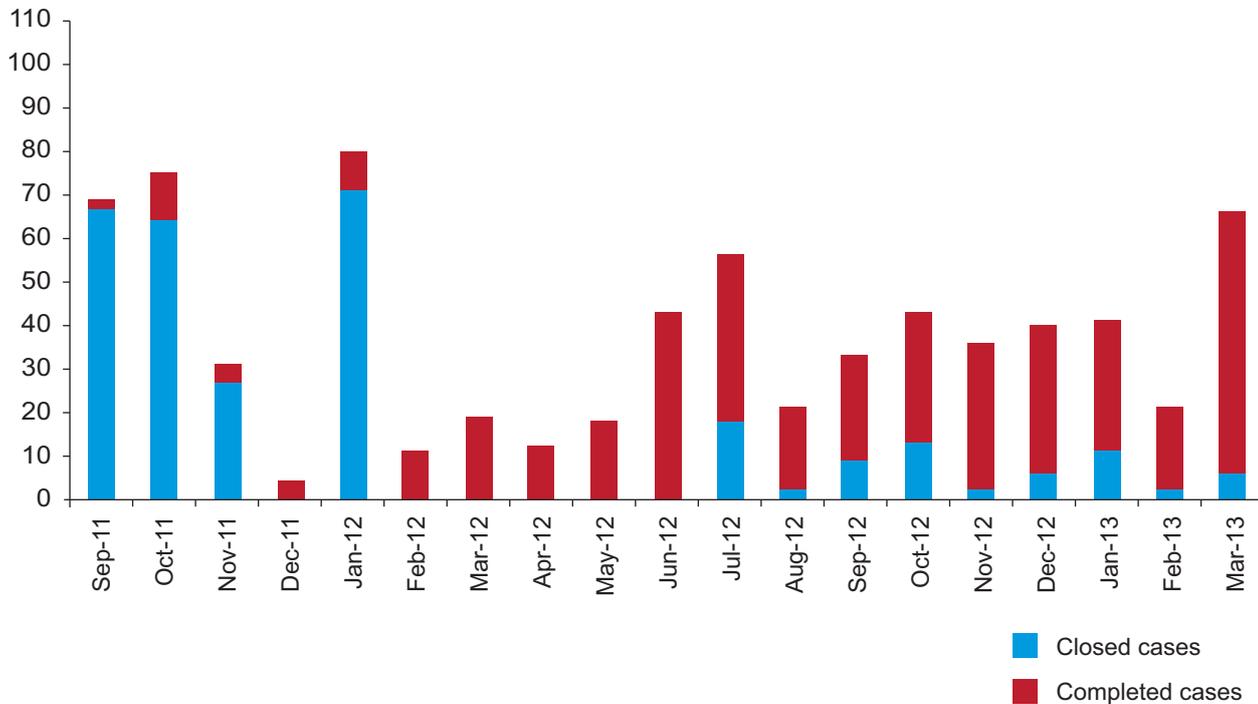
- 3.17** The project team has developed an action plan and a timetable which details the target number of cases that need to be completed in each six-month period. Quarterly reports on progress are also provided by the project director to the performance management group. However, an overarching business plan, including an assessment of key risks and how these could be addressed, was not developed at the outset of the project.
- 3.18** Between September 2011 and March 2013, 421 claims had been completed and a further 289 claims had been closed³⁰. Over the same period, the average number of cases completed or closed was 37 per month (Figure 17). This leaves 1,541 claims to be processed in the remaining 15 months of the initial three-year timescale for clearing all cases.
- 3.19** Of the completed cases, the majority (90 per cent) resulted in a full or partial settlement of the claim. The proportion of claims settled by matching (27 per cent) and in particular by panel (six per cent) is below the Powys project team's original expectations of 40 per cent and 30 per cent respectively. Over double the proportion of cases (67 per cent compared to 30 per cent) have been settled by negotiation than the project team had originally expected. Settling through negotiation, rather than referring to a panel, reduces the time taken to settle and is likely to be less stressful for the people making the claim.
- 3.20** Dealing with all outstanding cases by the deadline of June 2014 will be very challenging because, as at the end of March 2013:
- a** it requires the completion and closure of an average of 103 cases per month, which is far higher than the rates achieved to date (Figure 17);
 - b** review action had not started on 376 (24 per cent) of the 1,541 outstanding cases; and
 - c** a large majority of the 1,165 cases where action had started were cases that involved a solicitor, rather than Powys project staff, undertaking the initial work, whereas the remaining cases are dependent upon project staff, who are already stretched, undertaking the initial work.³¹

³⁰ Closed cases are where claimants are unable to provide proof or payment or proof of legal authority, or where they have decided to withdraw their application.

³¹ Where claimants are represented by a solicitor, the review process commences with the solicitor reviewing the evidence from health and social care records, and preparing a detailed chronology. For people not represented by a solicitor, this stage is carried out by Powys project special investigators.



Figure 17 - Retrospective cases closed and completed September 2011 to March 2013



Source: Powys project

The efficient processing of retrospective claims is constrained by difficulties in accessing clinical records and inconsistent practices relating to proof of payment

3.21 To process retrospective claims for CHC, the Powys project team requires access to the relevant clinical records that are held by individual health boards. The relevant case files, assessments and other documentation are often held in different locations within a health board, and the Powys project team considers that the time taken to obtain the relevant clinical records has contributed to the slow progress in completing retrospective claims. As a result, health boards are now required to provide the necessary records within six months of the case being activated

by the Powys project team. If the records are not provided by the six-month point, the Powys project team will undertake the review with the records that are available, which could favour the claimant.

3.22 A key part of the initial process of dealing with a retrospective claim is ensuring that the person making the claim is able to provide proof that they have paid the relevant care home fees. Many of the retrospective claims were submitted many years ago and had proof of payment requested and checked by NHS organisations at that time. The Powys project director told us that a lack of adequate scrutiny of the evidence provided and the need to adhere to relevant all-Wales financial guidance on proof of payment has led to problems

with some of the cases that the project has subsequently taken over. This had resulted in health boards not now accepting some original proof of payment evidence and decisions. Given the substantial passage of time that will have elapsed in some cases since the original proof of payment was supplied, it could be difficult for some claimants to find and provide the additional evidence now required.

Additional resources have been made available to reduce the risk of the national project overrunning and the Welsh Government has strengthened its monitoring of progress, but significant risks remain

3.23 In May 2012, the Powys project team estimated that, without additional resources, it would take until June 2016 to complete all outstanding cases, and that:

- a** additional direct costs of £1.7 million would be incurred, due to the need to employ staff for longer; and
- b** forecast interest payments on successful claims would be £1.6 million higher than originally estimated, due to the increased time taken to settle cases.

3.24 The projected overrun reflected, most significantly, problems in recruiting appropriately trained clinical advisors and in retaining special investigators. In addition, the project director told us that the timescales taken to clear cases were, in practice, far in excess of those originally estimated.

3.25 In July 2012, the Welsh Government (50 per cent) and health boards (50 per cent) made available an additional £1.6 million to increase the number of special investigators from seven to 16; the number of clinical advisors from 10 to 16; and the number of staff providing administrative support from three to six. The project director is confident that the increased staffing supported by the additional funding will be sufficient to ensure the project meets the June 2014 deadline.

3.26 Bimonthly Powys project group meetings that review the progress made have been held over the last two years. Welsh Government officials have attended these meetings since they commenced. From December 2012, the Welsh Government has prepared quarterly briefings for senior officials and the Minister for Health and Social Services on the progress made in dealing with retrospective claims by the Powys project and health boards. The briefings include data on the number of cases closed, completed and outstanding. The Welsh Government told us that it had also sought and received assurances from Powys Teaching Health Board that the project will meet the June 2014 deadline.

3.27 Despite the increased funding and strengthened monitoring by the Welsh Government, the recruitment and retention of Powys project team members remains a significant risk to the achievement of the June 2014 deadline. This is because, as at the end of April 2013:

- a** three clinical advisors and eight special investigators had left the team since June 2011;



- b** due to staff turnover, the number of special investigators needed to be in post to meet the deadline had increased from 16 to 18 whole-time equivalents;
- c** the full complement of required staff had not been reached – the number of clinical advisors in post had reached 13.4 of the planned 16 whole-time equivalents, and for special investigators this had reached 14 of the 18 whole-time equivalents; and
- d** although 1.8 whole-time equivalent clinical advisors and five whole-time equivalent special investigators had been appointed but had not then started in post, two special investigators were working their notice and a further three were likely to leave the team.

3.28 Once recruited, special investigators, who are often graduates in their first jobs, take time to be trained and become fully operational. Steps have been taken to minimise turnover by moving away from recruiting law graduates into special investigator posts, as they tended to move on quickly. However, as the project moves closer to its completion:

- a** further turnover is likely as staff look for their next job;
- b** notice periods, at four weeks for a special investigator and eight weeks for a clinical advisor, may lead to gaps before any replacement can be in post; and
- c** it may become increasingly difficult to fill what will become short-term posts.

Health boards are struggling to deal with the retrospective claims that they are responsible for processing

Health boards have received large numbers of retrospective claims and there is a risk that further claims may be made in the future

3.29 Health boards are responsible for all retrospective claims relating to claim periods between April 2003 and August 2010 that were received after the Framework came into force. They are also responsible for handling any disputes over decisions made under the Framework. In December 2012, the Welsh Government commenced quarterly monitoring and reporting of the progress with all retrospective cases, including those being dealt with by health boards. However, at the time of our review there was no central monitoring of the number of cases received by health boards, the number outstanding, or of the progress being made in processing them. In December 2012, the Welsh Government commenced quarterly monitoring and reporting of the progress with all retrospective cases, including those being dealt with by health boards.

3.30 In total, between 16 August 2010 and 30 September 2012, health boards received 1,264 retrospective claims and disputes against decisions made after August 2010. Betsi Cadwaladr University Health Board does not differentiate between retrospective claims and disputes, but across the other health boards, 87 per cent were for retrospective claims.

3.31 There was a large increase in the number of cases received during 2012. Across all health boards, 817 new retrospective cases and disputes were received between March 2012 and September 2012. Health board CHC leads told us that this trend continued with, for example, 119 new cases received in Betsi Cadwaladr University Health Board between 30 September 2012 and 9 November 2012. Health board CHC leads told us that the increase in cases related to retrospective cases and reflected:

- a** the handover of cases from the Powys project team following the change in responsibilities for retrospective cases; and
- b** the knock-on effect of the Department of Health in England announcing staged cut-off dates for all retrospective claims – with claimants in Wales not realising that the cut-off dates applied only to England.

3.32 Health board CHC leads were expecting to continue to receive new retrospective claims until the 31 March 2012 cut-off deadline in England was reached. In Wales, the Minister for Health and Social Services announced in November 2012 that the Welsh Government intends to introduce a rolling cut-off date for future claims³². On its introduction, this may result in a large number of claims being submitted as the first cut-off is likely to cover cases going back as far as April 2003. Thereafter, a rolling cut-off for making a claim, based on a maximum elapsed time from the original eligibility decision, should have a smaller impact on the number of claims.

3.33 There is potential for new challenges relating to health board decisions on the start date for funding cases previously assessed as eligible for CHC. One of the issues raised in a report by the Public Services Ombudsman for Wales concerned the point at which funding should commence, and the lack of Welsh Government guidance on this issue.³³ In response, the Welsh Government provided interim guidance on 30 April 2013³⁴ which confirmed that:

- a** a health board's responsibility for funding CHC commences at the point at which the multidisciplinary team met and completed the DST, rather than the date at which the scrutiny panel confirmed the multidisciplinary team's decision; and
- b** if there has been an 'unreasonable delay' in the multidisciplinary assessment process (defined as exceeding 56 days to reach a final decision, unless there are certain 'exceptional circumstances'), then there should be reimbursement of any payments for care made by the individual during the period of the unreasonable delay.

3.34 The guidance does not require health boards to review previous cases to ensure they comply with these requirements. However, individuals or their representatives may challenge health boards if they believe that at least one of these requirements was not met in the past.

³² Written Statement by the Welsh Government, *Progress in managing retrospective Continuing NHS Healthcare (CHC) claims*, 29 November 2012, Lesley Griffiths AM, Minister for Health and Social Services

³³ *The investigation of a complaint on behalf of Mrs S against Cardiff and Vale University Health Board*, A report by the Public Services Ombudsman for Wales, Case: 201101810, 24 April 2013

³⁴ MD/ML/001/11 Supplementary Guidance to Welsh Health Circular 015/2010: *Interim Guidance for National Continuing Healthcare Framework for Implementation in Wales May 2010*, Welsh Government, 30 April 2013



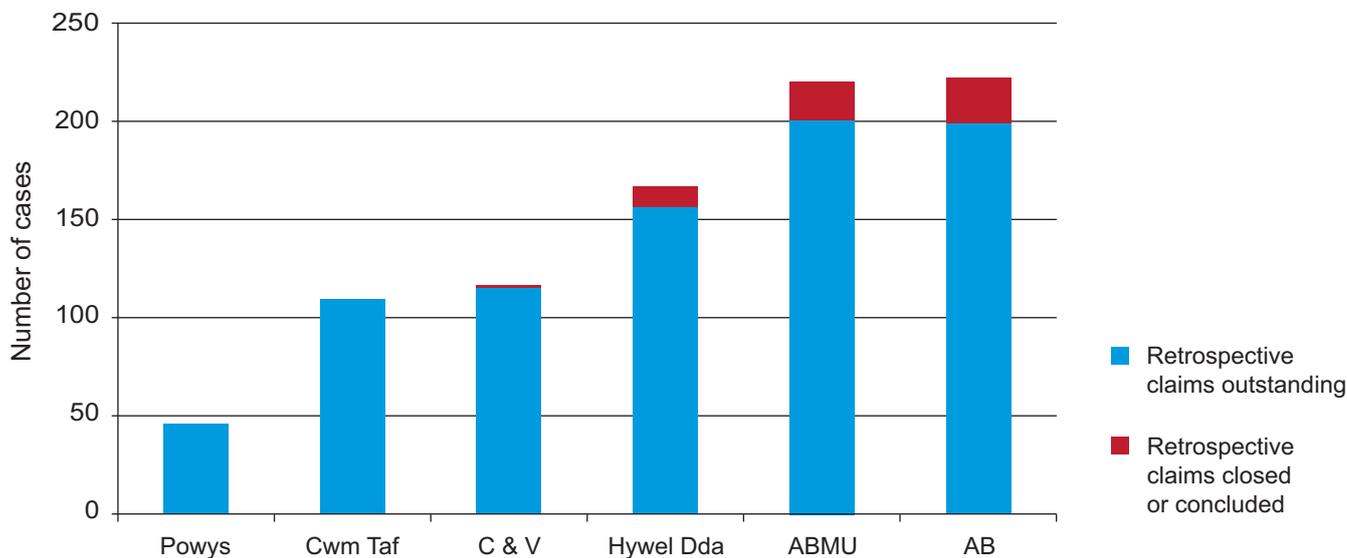
Health boards do not have a common process for dealing with retrospective claims, and have made very limited progress in clearing them

3.35 At the time that the Framework was issued, health boards were not expected to deal with such large numbers of retrospective claims, and they have not agreed a common approach for dealing with cases. The Welsh Government's interim guidance issued in April 2013 states that health boards should 'follow the same principles adopted by the Powys project of timely and efficient processes'. However, the guidance does not expand on this requirement, which is open to interpretation by health boards. Also, health boards have not agreed to adopt, for example, something similar to the matching and negotiating stages used by the Powys project team. The lack of a common approach increases the risk of inconsistent treatment of retrospective cases between health boards and with the Powys project team.

3.36 The Framework requires health boards to deal promptly with any request to reconsider decisions about eligibility for CHC. However, health boards are struggling to deal with the number of retrospective claims and disputes. As at the end of September 2012, only 164 (13 per cent) of the total 1,264 cases received had been cleared. Three out of every five completed retrospective cases had resulted in a full or partial repayment of fees, and two out of every five completed disputes were successful.

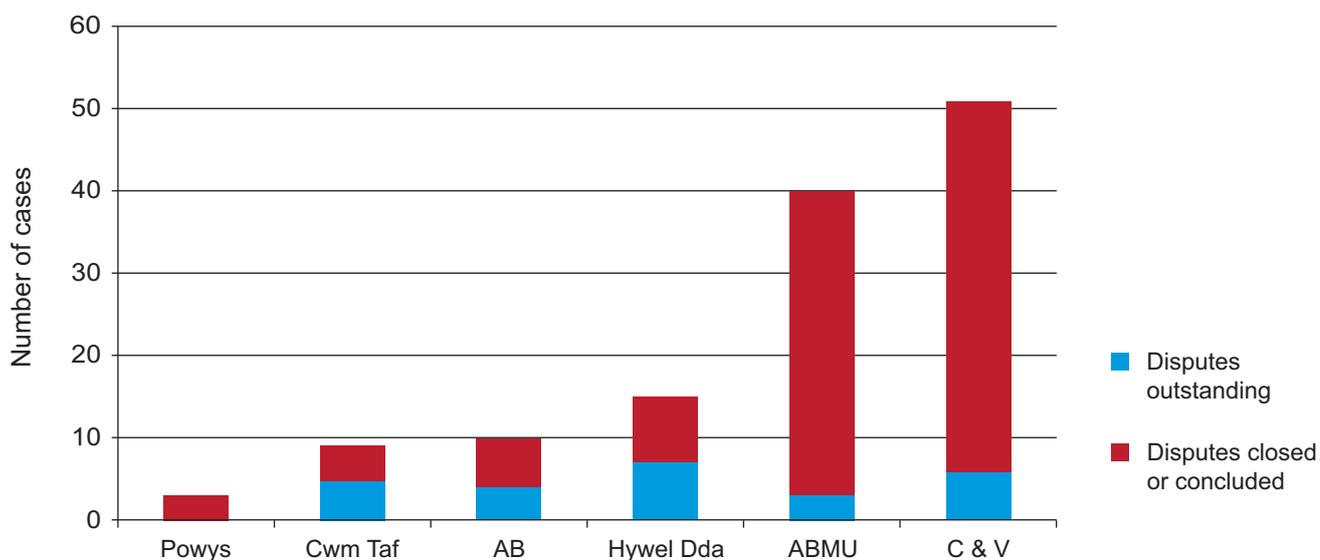
3.37 Health boards have made least progress in clearing retrospective cases. Across the six health boards that could provide disaggregated data, only 53 of the 881 retrospective cases had been concluded by the end of September 2012 (Figure 18). In contrast, 103 of the 129 disputes had been concluded during the same time period (Figure 19). Betsi Cadwaladr University Health Board could not provide disaggregated data, but has received the second-highest number of retrospective cases and disputes, and between August 2010 and September 2012 had cleared only nine out of 252 cases.

Figure 18 - Retrospective cases concluded between August 2010 and September 2012 and outstanding as at September 2012 by health board



Note
 Betsi Cadwaladr University Health Board could not disaggregate data for retrospective cases and disputes
 Source: Wales Audit Office survey of health boards, October 2012

Figure 19 - Disputes concluded between August 2010 and September 2012 and outstanding as at September 2012 by health board



Note
 Betsi Cadwaladr University Health Board could not disaggregate data for retrospective cases and disputes
 Source: Wales Audit Office survey of health boards, October 2012



3.38 The progress made by different health boards in dealing with retrospective claims and disputes is mixed. The total number of retrospective claims and disputes concluded between August 2010 and September 2012 varied from three at Powys Teaching Health Board to 56 at Abertawe Bro Morgannwg University Health Board. The proportion of all cases that have been concluded varies from less than four per cent at each of Cwm Taf and Betsi Cadwaladr Health Boards to 28 per cent in Cardiff and the Vale Health Board.

3.39 The Welsh Government told us that it was made aware of the backlog of work in health boards in autumn 2012. In response, it raised the issue with the relevant health boards and discussed it with the National CHC Advisory Group.

It is unclear whether health boards have now allocated sufficient resources to deal with the large number of retrospective claims and disputes in a timely way

3.40 On the basis of the slow rate at which retrospective claims are being cleared, all health boards had not given sufficient priority, or allocated appropriate staff resources, to deal with retrospective claims and disputes. For example, as at the end of March 2012, three of seven health boards had only concluded four or fewer cases since August 2010. When we visited Betsi Cadwaladr University Health Board in January 2012, staff acknowledged that they had insufficient resources to deal with the volume of cases. This was compounded by operational staff giving little priority to the work needed to support the central team in processing cases. The lack of adequate resources had also resulted in the health board:

- a** struggling to keep on top of related correspondence, and having to react to requests for updates on progress from individuals and their solicitors; and
- b** prioritising cases that are likely to be quicker to conclude, rather than by chronological order.

3.41 An increase in staff resources should increase the rate at which cases are completed. We asked health boards to provide details of the staff resources allocated to retrospective claims and disputes, as at March 2012 and as at September 2012. Establishing the level of staff resources can be difficult because staff can work on retrospective claims and disputes as part of a much wider role. Where this was the case, we asked health boards to estimate the proportion of time spent on dealing with retrospective claims and disputes. We found that:

- a** health boards, such as Cwm Taf and Powys, that had allocated the lowest resources had also concluded the lowest number of cases (four and three respectively, compared to 31 cases on average across the other health boards);
- b** three health boards increased their staff resources between March 2012 and September 2012, including one (Cardiff and Vale University Health Board) that had doubled its resources from three to six whole-time equivalents;
- c** three health boards had maintained their level of allocated resources over the same period; and
- d** one health board (Betsi Cadwaladr) had lost but not replaced three whole-time equivalent staff.

3.42 In January 2013, all health board CHC leads told us that business cases to increase staffing to deal with retrospective claims and disputes had either been agreed or were being considered by their health board. However, it is too soon to tell whether the proposed increase in resources will be sufficient to deal with the volumes of outstanding cases in a timely manner. As at the end of September 2012, more than 1,050 retrospective cases (which includes an estimated figure for Betsi Cadwaladr University Health Board) were outstanding across Wales. The number of outstanding cases may well have increased since September 2012, as it is likely that the number of new cases received since this time will have outstripped the number of completed cases.

Some health boards were slow to set up the dispute processes outlined in the Framework, and independent review panels are not always operating effectively

3.43 The Framework requires health boards to agree local processes for handling and resolving disputes against CHC eligibility decisions, including timescales, and to make these available to the public. Our analysis of relevant health board documents provided to us in the final quarter of 2011 found that three health boards had produced standalone policies for the dispute process, one of which was still at the draft stage. A further three health boards had incorporated local arrangements for disputes into their main CHC policy document, although one of these was also still at the draft stage. The final health board had not detailed any local arrangements, and its CHC policy simply repeated the Framework's requirements relating to disputes.

3.44 Policies and procedures relating to disputes, where they existed, were not always explicit about the target timescales for dealing with individual cases. Betsi Cadwaladr University Health Board told us that target timescales had not been included in its written procedures because of the extended period it was taking to resolve disputes.

3.45 The extent to which local policies relating to disputes have been made available to the public is variable. In their responses to our survey, Powys Teaching Health Board stated that its policy had not been made public as it had not then been ratified by its board; and Cardiff and Vale University Health Board said that it had not made the relevant information widely available to the public, although it does provide this information on request. However, it is difficult to see how some of the other health boards that reported making the information available to the public were achieving this. For example, two health boards where a policy was still in draft stated that the relevant information had been made publicly available.

3.46 The Framework requires each health board to establish an independent review panel to consider disputes from individuals against CHC decisions. Two of the three health boards we visited did not establish independent review panels until November 2011 (Hywel Dda Health Board) and February 2012 (Betsi Cadwaladr University Health Board). Our survey of all health boards and fieldwork visits to three of them identified some other requirements of the Framework relating to the operation of independent review panels that were not being met, including:



- a** Powys Teaching Health Board reported that it had not designated an individual to be responsible for administering the review procedure, for example by collecting information for the independent panel by interviewing appellants, family members and carers;
- b** in Betsi Cadwaladr University Health Board and Powys Teaching Health Board the independent review panel did not routinely have access to independent clinical advice; and
- c** in Betsi Cadwaladr University Health Board there was no facility to properly record the panel's deliberations.

3.47 In investigating complaints, the Public Services Ombudsman for Wales has also raised concerns about the operation of some independent review panels. For example, in one case the ombudsman concluded that a panel's approach had been too restrictive and there was too little consideration and application of CHC guidance; and in another, the ombudsman expressed concern that a panel had failed to identify extensive and significant flaws in the information that had been provided to it.

Appendix 1 - Study methods

In undertaking the work, we gathered evidence from a broad range of sources between November 2011 and October 2012.

Health board and local authority surveys and document reviews

All seven health boards completed a survey in November 2011, providing information on the progress made locally in implementing the Framework. The survey covered governance arrangements; assessment, decision making, review, and dispute processes; and joint working arrangements with social services.

At the same time, we also undertook a survey of local authorities. This covered the requirements the Framework places on social services, including joint working arrangements with health boards. Eighteen of the 22 local authorities replied to the survey. We did not receive a response from Cardiff Council, the Isle of Anglesey County Council, Merthyr Tydfil County Borough Council, and Vale of Glamorgan Council. Powys County Council replied to the survey but only answered two of the 18 questions.

We also requested a range of documents from health boards, including local CHC policies and protocols, performance monitoring reports, and terms of reference and minutes of scrutiny and independent dispute panels. These were provided by all health boards between November and December 2011.

Fieldwork visits

We visited Hywel Dda, Aneurin Bevan and Betsi Cadwaladr University Health Board areas between December 2011 and January 2012. We undertook a case file review in each area to examine the extent to which Framework requirements were being met. In total we examined 212 case files, covering people with a mix of mental health, learning disabilities and general health needs.

We also interviewed a cross-section of staff in each area. Within social services we met with the director of social services and a selection of operational managers and social workers. Within health boards, we interviewed the director with lead responsibility for CHC, CHC managers, and a selection of operational managers, nurse assessors, community and hospital nurses, consultants, and chairs of the independent review panels.

In addition to the three health board areas, we also visited the national CHC project for retrospective claims hosted by Powys Teaching Health Board and interviewed the lead director.



Workshop for health board CHC leads

In April 2012, we ran a workshop for health board CHC leads. All health boards attended the workshop, which was designed to gather views on what elements of the Framework were working well, what issues existed, and what the priorities for action should be. The workshop allowed all health boards to input their views to the review, and a report summarising the output from the day was issued to participants.

Data gathering and analysis

We gathered and analysed a range of data from health boards. In May 2012, all health boards provided data on the number of NHS-funded nursing care and CHC cases at the end of the last four financial years. In October 2012, all health boards provided data on the number of disputes and retrospective cases and the staff resources available to deal with these. We also analysed health board financial accounts to generate data on CHC and NHS-funded nursing care expenditure each year between 2004-05 and 2011-12. To help our understanding of what lay behind the data on the number of cases and expenditure patterns, we met with the CHC management team from Abertawe Bro Morgannwg University Health Board.

We also analysed the database used by the national CHC project for retrospective claims that records the progress and outcome of individual cases.

Stakeholder views

A range of local and national organisations providing support and advocacy to people with complex care needs were given an opportunity to provide a written submission of their experiences and views on CHC. We received written submissions from Age Concern, Alzheimer's Society, Crossroads, and the Older People's Commissioner for Wales. The submissions were received between July and November 2012, with some organisations including case studies or individual experiences.

As part of our fieldwork visits, we examined recent complaints relating to CHC at the three health boards. We reviewed a variety of reports from the Public Services Ombudsman for Wales, and met with his team in November 2012. We also met with Hugh James Solicitors at the start of the review and in May 2012 to gather their views and experiences of CHC.

Welsh Government and national groups

At a national level, we interviewed officials from the Welsh Government who have responsibility for CHC. We attended and reviewed the outputs from the CHC National Programme, the Complex Care Forum, and the National CHC Implementation Group and its successor, the National CHC Advisory Group.

Appendix 2 - Timeline of key events

Date	Key event
1999	<p>The Coughlan Court of Appeal judgement ruled on the limits of provision of nursing care (in a broad sense ie, not just registered nursing care) by local authorities for a person living in residential accommodation. Key points from the judgement include that:</p> <ul style="list-style-type: none"> • provision would be appropriate if the nursing services are 'merely incidental or ancillary to the provision of the accommodation' and 'of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide'; • a local authority is excluded from providing services where the NHS has in fact decided to provide those services; • where a person's primary need is a health need, the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority; and • an assessment of whether a person has a primary health need should involve consideration of not only the nature and quality of the services required but also the quantity or continuity of such services.
2001	<p>The Health and Social Care Act 2001 stated that care from a registered nurse cannot be provided by the local authority as part of community care services. Such care was now to be provided within NHS-funded nursing care. Persons who have been found not eligible for CHC could be assessed for NHS-funded nursing care.</p>
February 2003	<p>A report by the Health Service Ombudsman on long-term care found that a number of people had been wrongly charged for elements of their care when they should have been treated as eligible for CHC and all their care provided free by the NHS. The ombudsman recommended that efforts should be made to remedy any financial injustice to patients where the CHC criteria, or the way they were applied, were not clearly appropriate or fair. The recommendation was accepted in Wales and England.</p>
April 2003	<p>Health authorities in Wales replaced by 22 Local Health Boards (LHBs).</p>
June 2004	<p>Arrangements were established with what is now Powys Teaching Health Board which allowed people to claim retrospectively that they (or their deceased relative) were eligible for CHC but were wrongly charged for care between 1996 and 2003. Claims for later periods were processed by the relevant LHB where the claimant lived.</p>
August 2004	<p>The first Framework for CHC and associated guidance issued. The Framework and associated guidance outlined the key criteria and other issues to be taken into consideration when making decisions about eligibility for CHC.</p> <p>The Framework stated that eligibility for CHC depends upon the nature and extent of health care needs and of the health care inputs required. Whether an individual is eligible for CHC depends on the nature, complexity, predictability, intensity and amount of their health care needs and of the health care inputs which they require, regardless of diagnosis.</p> <p>The Framework looked to address the issues raised in relation to the provision of CHC by the report of the Health Service Ombudsman on long-term care, and to ensure local processes were compliant with legal requirements and judgements.</p>



Date	Key event
2004-05	A 13.8 per cent increase in CHC expenditure within Wales compared with the previous year (excludes provisions for any future liabilities arising from challenges to eligibility decisions).
January 2006	Grogan judgement on the interaction between CHC and NHS-funded nursing care. The court concluded that in assessing whether Mrs Grogan was entitled to CHC, the care trust did not have in place or apply criteria which properly identified the test or approach to be followed in deciding whether her primary need was a health need.
2005-06	A 26.3 per cent increase in CHC expenditure within Wales compared with the previous year (excluding provisions).
October 2006	The Welsh Government issues revised guidance on CHC. This provided advice and recommended actions to be taken by LHBs following the Grogan judgment. This was an interim step whilst the full guidance on CHC was amended.
2006-07	A 31 per cent increase in CHC expenditure within Wales compared with the previous year (excluding provisions).
October 2007	Revised CHC Framework, taking account of the Grogan judgement, issued in England.
February 2008	The Welsh Government issues a revised draft CHC Framework for consultation.
2007-08	A 50.7 per cent increase in CHC expenditure within Wales compared with the previous year (excluding provisions).
August 2008	St Helens judgement on responsibility for decision making around CHC eligibility. The court ruled that the NHS is the primary decision maker when it comes to deciding whether a person has a primary health need.
2008-09	A 42.2 per cent increase in CHC expenditure within Wales compared with the previous year (excluding provisions).
July 2009	Following a review, the English Framework is revised by adding further clarity and tools, but the revisions do not change principles or eligibility criteria.
2009	Following an announcement by the Welsh Government that no new applications relating to the period up to April 2003 would be considered if received after 4 December 2009, there was a considerable influx of new claims. Claimants who had registered by 4 December 2009 were then given until 17 May 2010 to provide the required legal proof of title and proof of payments for care to allow the claim to be investigated.
2009-10	A 13.2 per cent increase in CHC expenditure within Wales compared with the previous year (excluding provisions). A 2.8 per cent increase in the number of CHC cases at 31 March 2010 (excludes Betsi Cadwaladr University Health Board).
May 2010	The Welsh Government's revised Framework for CHC issued, with an implementation date of 16 August 2010. This is based on the English Framework, but with some key differences in the approach and tools.

Date	Key event
2010-11	A 10.7 per cent increase in CHC expenditure compared with the previous year (excluding provisions). A 1.6 per cent reduction in the number of CHC cases as at 31 March 2011 (excludes Betsi Cadwaladr University Health Board).
June 2011	The scope of the Powys project is extended to include retrospective claims relating solely to the period between 1996 and April 2003; claims which relate to periods after April 2003 and up to 15 August 2010; and claims which straddle these two periods. Claims which relate solely to the period after 16 August 2010 continue be dealt with by the relevant LHB.
September 2011	The Welsh Government confirms to those LHBs attending the National CHC Implementation Group a change in the responsibilities for retrospective claims. LHBs were now responsible for any retrospective claim that was received after 16 August 2010.
2011-12	5.8 per cent decrease in CHC expenditure on previous year (excluding provisions). 2.6 per cent reduction in cases at 31 March 2012 (excludes Betsi Cadwaladr University Health Board).
July 2012	The Welsh Government makes available an additional £1.6 million to increase staffing levels with the Powys project and to help ensure all retrospective cases are completed by June 2014.



Appendix 3 - Approaches to CHC and paying for social care across the UK

Post devolution in Scotland, Northern Ireland and Wales, different approaches and charging arrangements for people with complex care needs have developed across the United Kingdom.

Current arrangements

Issue	Current arrangements across the UK
<p>Eligibility for CHC</p>	<p>All parts of the UK have continuing healthcare in which all services are provided free and funded by the NHS. However, there are distinct differences in Scotland compared to the rest of the UK.</p> <p>Wales, England and Northern Ireland use the primary health need approach and CHC funding can cover care costs in a person's own home or in a care home.</p> <p>In Scotland, CHC funding is available for people requiring a very high level of specialist treatment and it is expected that care will be provided in a hospital ward, hospice or a contracted inpatient bed (which may be based in a care home).</p>
<p>Guidance on CHC</p>	<p>Wales, England and Scotland have dedicated and detailed guidance on CHC. In Northern Ireland less specific guidance is incorporated into a policy on care management, provision of services and charging policy.</p>
<p>NHS-funded nursing care</p>	<p>NHS-funded nursing care refers to the financial contribution paid by the NHS towards the cost of meeting assessed nursing care needs and is provided in all parts of the UK.</p>
<p>Personal care and accommodation costs in nursing homes</p>	<p>If someone is eligible for CHC, the costs of personal care and accommodation in care homes are free in Wales, England and Northern Ireland (and in Scotland when this is a contracted inpatient bed). People not eligible for CHC are means tested to see whether they or the local authority pay for the personal care and accommodation element of the care home fee.</p> <p>In Scotland, all people over 65 have free personal care. People under 65 are means tested for personal care costs, and all people are means tested for accommodation costs.</p>
<p>Means testing</p>	<p>Means testing is based on a savings and assets threshold which, if exceeded, results in the individual being responsible for care home costs.</p> <p>The upper savings and assets limit at which someone is responsible for all care home costs is the same in Wales, England and Northern Ireland (£23,250) but is higher in Scotland (£24,750).</p> <p>There is no 'tapering' in Wales, but in the rest of the UK there is a lower limit (typically set at around £14,250) at which point people begin to contribute on a sliding scale towards care home costs.</p>

Future arrangements

The funding and charging arrangements are to change in England. Launched in July 2010, the Commission on Funding of Care and Support was an independent body tasked with reviewing the funding system for care and support in England. It was chaired by Andrew Dilnot, and the report, published in July 2011³⁵, found that the current funding system is in urgent need of reform: it is hard to understand, often unfair, unsustainable, and people are left exposed to potentially 'catastrophic care costs' with no way to protect themselves. The report's recommendations included:

- that an individual's lifetime contributions towards their social care costs – which are currently potentially unlimited – should be capped at £35,000; and
- the means-tested threshold, above which people are liable for their full care costs, should be increased to £100,000.

In February 2013, the UK Government announced that from April 2017 funding arrangements for care and support in England will change with:

- a cap of £75,000 on an individual's lifetime contribution towards his or her social care costs, excluding any 'room and board' accommodation costs; and
- an increase of the means-tested threshold, above which people are liable for their full care costs, to £123,000.

The Welsh Government issued a green paper for consultation on the options for Wales in November 2011³⁶, and are presently considering whether there should be reforms in Wales that build on the Dilnot proposals.

³⁵ *Fairer Care Funding*, The Report of the Commission on Funding of Care and Support, July 2011

³⁶ *Paying for Care in Wales: creating a fair and sustainable system*, Green Paper consultation on options for reform, Welsh Assembly Government, November 2011



Appendix 4 - Improving the Framework

This report identifies a number of areas where the current guidance could be improved. These are summarised below.

Where clearer and more explicit guidance is needed

The quality of the guidance could be improved by combining the Framework and the separate practice guidance into one document. Clearer guidance is also needed in respect of:

- how the Framework should be applied for people with a learning disability or a mental health problem;
- joint funding arrangements;
- the monitoring of care home contracts;
- the local policies and protocols that need to be in place in health boards; and
- scrutiny arrangements in health boards, to encourage consistency between panels, local authority engagement and communication, and consistency of scrutiny regardless of the care costs involved.

Where there are gaps in guidance

There are gaps in the guidance in respect of:

- the CHC performance measures health boards should capture and report;
- the maximum target time within which health boards should resolve disputes with claimants, and how this is measured; and
- whether and how health boards should scrutinise cases that are not put forward to be assessed for CHC or that are deemed ineligible for CHC.

Where the guidance should be reassessed and, if appropriate, revised

In the light of health boards' experiences in implementing the Framework, the Welsh Government should reassess the appropriateness of its guidance in respect of:

- the target time for completing the CHC assessment and decision-making process;
- the frequency of CHC reviews, in the light of its assessment of the less onerous requirements in England;
- the requirement that each specialist gains consent for their individual assessment, as this is clearly not being achieved in Wales and is not a policy requirement in England; and
- alternative ways in which health boards are required to involve individuals and their family/carers in the DST process, in addition or as an alternative to them attending DST meetings.

Glossary of terms

Care home

An establishment registered under the Care Standards Act 2000 to provide accommodation, together with nursing or personal care, for certain categories of persons.

Care package

A combination of support and services designed to meet individual's assessed needs.

Care Programme Approach

The Care Programme Approach is used across Wales for people with a mental health problem. A health or social services professional is appointed to co-ordinate the assessment and care planning for an individual. In consultation with the individual, their needs are assessed and a care plan produced eight key areas of life: accommodation; education and training; finance and money; medical and other forms of treatment; parenting or caring relationships; personal care and physical well-being; social cultural or spiritual; and work and occupation.

Carers

Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is usually unpaid. This excludes paid care workers and volunteers.

Cognition

The higher mental processes of the brain and the mind including memory, thinking, judgement, calculation, visual spatial skills etc.

Cognitive impairment

Cognitive impairment applies to disturbances of any of the higher mental processes, many of which can be measured by suitable psychological tests. Cognitive impairment, especially memory impairment, is the hallmark and often the earliest feature of dementia.

Continuing NHS Healthcare

A complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need. CHC can be provided in any setting. In a person's own home, it means that the NHS funds all the care that is required to meet their assessed health and social care needs to the extent that this is considered appropriate as part of the health service. This does not include the cost of accommodation, food or general household support. In care homes, it means that the NHS also makes a contract with the care home and pays the full fees for the person's accommodation as well as their care.



Disputes between organisations

These refer to disputes between health boards and local authorities about eligibility for CHC.

Disputes from individuals

In this report, we use the term to refer to challenges made by individuals against CHC eligibility decisions made under the revised Framework since August 2010. Individuals may ask that the decision on eligibility for CHC is reconsidered. These requests are dealt with by individual health boards.

Independent Living Fund

The Independent Living Fund provides money to help disabled people live an independent life in the community rather than in residential care. People can use payments to employ a carer or personal assistant to give personal and domestic care or pay a care agency to provide personal care and help with domestic duties. The scheme is now closed to new applicants, and, if stopped, cannot be reinstated.

Individuals

In this report, we use the term 'individuals' to refer to people who are being assessed or have been assessed for CHC.

Long-term care

This is a general term that describes the care which people need over an extended period of time, as the result of disability, accident or illness to address both physical and mental health needs. It may require services from the NHS and/or social care, and can be provided in a range of settings, such as an NHS hospital, a care home (providing either residential or nursing care), hospice, and in people's own homes.

Mental capacity

The ability to make a decision about a particular matter at the time the decision needs to be made. The legal definition of a person who lacks capacity is explained in section 2 of the Mental Capacity Act 2005: 'A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain'.

Multidisciplinary

Multidisciplinary refers to professionals across health and social care and the third sector who work together to address the holistic needs of their patients/clients in order to improve delivery of care and reduce fragmentation.

Multidisciplinary team

A team usually from both health and social care backgrounds. It does not refer only to an existing multidisciplinary team such as on an acute ward. It also includes those who have an up-to-date knowledge of the individual's needs, potential and aspirations.

NHS-funded nursing care

The provision of NHS-funded nursing care derives from section 49 of the Health and Social Care Act 2001, which excludes nursing care by a registered nurse from the services which can be provided by local authorities. Section 49 was partially implemented with effect from December 2001, introducing NHS-funded nursing care for self-funders and those residents who paid the majority of their care costs themselves. The full implementation of section 49 extends the scope of NHS-funded nursing care to cover all those persons currently assessed as requiring care by a registered nurse in care homes who were formerly the responsibility of local authorities.

Retrospective claim

In this report, we use the term to refer to challenges made by individuals against CHC eligibility decisions that were made before the Framework came into force in August 2010, and that resulted in the individual (or their deceased relative) being wrongly charged for care. Retrospective claims received before the Framework are dealt with by a national project team, and those received after the Framework are dealt with by health boards.

Social care

Social care is care provided to support an individual's social needs. It refers to the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships. Social care services are provided for people who need help/assistance to live their lives as independently as possible in the community (either at home or in a care setting), people who are vulnerable and people who may need protection. Local authorities, the voluntary sector and the independent sector can provide social care.

Social services

Primary responsibility for the delivery of community social care services rests with local authorities. Social services are provided by 22 local authorities in Wales. Individually and in partnership with other agencies, they provide a wide range of care and support for people who are deemed to be in need.

Social work

Social work is a professional activity/service provided by a registered social worker. It is an activity that can enable individuals, families and groups to identify personal, social and environmental difficulties adversely affecting them. It is a range of activities that can provide supportive, rehabilitative, protective or corrective action. This can include care management, social care assessment and planning and counselling.

Unified Assessment Process

This describes the common assessment process for health boards and local authorities. It promotes a holistic approach to assessment, with the aim of ensuring more effective joint working and to prevent people being serially assessed and asked for the same information by different agencies.