A GUIDE TO THE LAW ON NHS CONTINUING CARE AND NHS FUNDED NURSING CARE

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1. What is NHS Continuing Healthcare ("CHC")?

1.1 This chapter is a general guide to the law and practice around NHS Continuing Healthcare (referred to in this chapter as "**CHC**"). CHC is the name given to a package of care that is arranged and funded solely by the NHS for individuals who are (generally) not in hospital and who have complex ongoing healthcare needs to such an extent that the patient can be described as having a "primary health need"[1]. The Department of Health has published a leaflet[2] summary about CHC which is a good start to explaining the complexities of a service that is widely misunderstood.

1.2 The core legal documents governing CHC are Part 6 of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 ("**the 2012 Regulations**") and the "National Framework on NHS Continuing Healthcare and NHS-funded Nursing Care" ("**the National Framework**")[3] which was published in November2012 and came into effect on 1 April 2013. In March 2018, shortly before this book went to press, the Department of Health published a revised version of the National Framework[4] which will come into effect in October 2018. The law set out in this chapter is based on the 2012 version of the National Framework. However readers who are considering matters related to CHC after 1 October 2018 should review matters in the light of the new framework. A full description of the effect of the new National Framework will be provided in the second edition of this book.

1.3 The present version of the National Framework defines NHS Continuing Care as follows:

[1] See http://www.nhs.uk/chq/Pages/2392.aspx.
[2] See https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/193700/NHS_CHC_Public_Information_Leaflet_Final.pdf
[3] See https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf
[4] See https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf

> "'NHS continuing healthcare' means a package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a 'primary health need' as set out in this guidance. Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. The actual services provided as part of the package should be seen in the wider context of best practice and service development for each client group. Eligibility for NHS continuing healthcare places no limits on the settings in which the package of support can be offered or on the type of service delivery"

1.4 CHC is thus a package of health and social care services (and possibly accommodation if that is part of the patient's needs) to meet a patient's reasonable requirements for such services, all of which is funded by the NHS. This is shown at paragraph 25 of the National Framework which provides:

> "Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed needs – including accommodation, if that is part of the overall need"

1.5 A decision that the patient is eligible for NHS CHC means, in practice, that the whole of the care package for that patient will be funded by the NHS, as opposed to the costs being shared between the NHS and social services authorities (i.e. the local authority). This has the practical benefit for patients (and their families) that none of the services for a CHC patient are designated as being "means tested" services under the social care system but are provided by the NHS, i.e. generally free of charge. Frequently CHC patients are provided with care in care homes as opposed to being provided with care directly by staff employed by NHS bodies because Clinical Commissioning Groups contract with private care homes to provide the required services (as they are permitted to do under section 10 of the NHS Act[5]). The care home fees thus become costs that are required to be met by the local Clinical Commissioning Group ("**CCG**").

2 A brief history of government policy concerning CHC.

2.1 The concept of NHS Continuing Care emerged out of concerns in the 1980s and early 1990s that patients with complex conditions were being treated outside NHS hospital where the same patients would previously have received this care within an NHS hospital. Patients who receive their health and social care in an NHS hospital are provided with their medicines, food, accommodation and social care free of charge. Although this is often taken for granted, the provision of food, accommodation and social care is the provision of "non-medical" support to hospital patients, funded by the NHS. Thus, the provision of food, accommodation and social care funded by the NHS comes as part of an overall "NHS hospital" package of care. However, the NHS does not generally provide "non-medical" support for patients outside an NHS hospital environment. Where such services are needed by patients, they are either paid for by patients themselves or are community care services which are the responsibility of a local authority under the Care Act 2014. Community care services are subject to means testing and, for those with means, to charges.

2.2 When the NHS was created a large number of individuals were provided with long term care in NHS hospitals. There were "back-wards" in NHS hospitals which provided long term care to the elderly. Although it is dangerous to generalise, these "patients" were often the frail elderly and often had minimal acute medical input, patients with learning difficulties who mainly needed social care and patients with long term conditions that were managed within a hospital environment. In the early 1950s the NHS maintained 32,000 TB beds and had a considerable estate of "mental health" institutions providing care for those with learning difficulties, many of whom would not now be considered to have a mental health disorder. Most patients with learning difficulties had social care needs but far fewer had physical or mental health needs. There is an excellent history of the changes to the NHS and how these long term beds were phased out in the King's Fund interim report "*A new settlement for*

[5] The National Health Service Act 2006

health and social care[6]". This explains how, over an extended period, starting in the 1960s, these long term beds were phased out, with many former long stay patients being provided with social care services in place of an NHS bed (often called "care in the community").

2.3 There are 2 crucial differences between NHS services and community care services. First, as far as the service user/patient is concerned, NHS services are largely funded out of government money (i.e. provided by taxpayers) and thus provided free of charge to the individual patient. In contrast, community care services have always been subject to a means tested contribution being paid by the service user[7]. Secondly, NHS services are funded by NHS bodies exercising target legal duties. In contrast, community care services are provided by local social services authorities (unitary Councils or County Councils) under duties imposed by the Care Act 2014. These are not target duties but are duties owed by local authorities directly to individual service users. Hence, one effect of changing medical patterns of care which moved medical treatment for patients with complex conditions out of the hospital environment was to transfer responsibility for the duty to provide accommodation and social care away from the NHS and, at least in a majority of cases, to a local authority. This change also changed the services from being "free at the point of use" to being a service where the user had to pay, subject to a means test. But, that statutory change also resulted in the costs of provision of these services being transferred from the NHS (i.e. nationally managed state funds) to either patients or local authorities.

2.4 The first relevant Guidance that attempted to describe the dividing line between statutory health and social care responsibilities was Health Service Guidance (92)50 which was issued when the National Health Service and Community Care Act 1990

[6] See http://www.kingsfund.org.uk/press/press-releases/independent-commission-calls-new-settlement-health-and-social-care
[7] This distinction goes back to the National Assistance Act 1948 and the National Health Act 1946, both of which emerged out of the 1941 Beveridge Report.

came into force in April 2003. The 1990 Act imposed a statutory duty on social services authorities to conduct assessments of the needs of service users who required community care services. The coming into force of the 1990 Act was accompanied by a guideline document, HSG(92)50, issued by the NHS Management Executive to district health authorities called "*Local authority contracts for residential and nursing home care: NHS related aspects*". It provided:

> "This guidance sets out district health authority and local authority responsibilities, from April 1993, for funding community health services for residents of residential care and nursing homes who have been placed in those homes by local authorities."

2.5 The guidance proposed a distinction between "*specialist"* nursing services, which would continue to be provided by the NHS, and "*general nursing care*", which the guidance proposed should be for the local authority to fund. The Guidance said:

> "Full implementation of the White Paper 'Caring for People' will mean that local authorities will have responsibilities for purchasing nursing home care for the great majority of people who need it and who require to be publicly supported. When, after April 1993, a local authority places a person in a nursing home after joint health authority/local authority assessment, the local authority is responsible for purchasing services to meet the general nursing care needs of that person, including the cost of incontinence services (e g laundry) and those incontinence and nursing supplies which are not available on NHS prescription. Health authorities will be responsible for purchasing, within the resources available and in line with their priorities, physiotherapy, chiropody and speech and language therapy, with the appropriate equipment, and the provision of specialist nursing advice, e.g. continence advice and stoma care, for those people placed in nursing homes by local authorities with the consent of a district health authority. Health authorities can opt to purchase these services through directly managed units, NHS trusts, or other providers including the nursing home concerned. Health authorities continue to have the power to enter into a contractual arrangement with a nursing home where a patient's need is primarily for health care. Such placements must be fully funded by the health authority"

2.6 The Guidance thus suggested that the NHS would continue to have a power (but possibly not a duty) to purchase a nursing place for an NHS patient where the

"*patient's need is primarily for health care*". However, the guidance gave no indication as to how the NHS was supposed to determine whether a patient's needs were primarily for healthcare as opposed to having a primary need for social care. It was also unclear from this Guidance whether the NHS would have a power or only a duty to provide a nursing home place (and hence a package including accommodation and social care services) for a patient whose needs were primarily for healthcare.

2.7 The practical consequence of this policy was that, once patients with complex conditions moved out of the NHS hospital environment, accommodation, social care and support was generally funded by patients themselves or by local authorities. Health authorities limited themselves to providing "specialist" health services, but looked to the local authority to provide accommodation and social care services pursuant to their community care obligations.

2.8 Further Guidance was issued in 1995 called "*Continuing Care: NHS and Local Councils' responsibilities*". The 1995 guidance included some general principles which attempted to define where the line lay between the duties of local authorities and those of NHS bodies. It said the NHS was responsible for arranging and funding in-patient continuing care in a hospital or nursing home, on a short or long term basis, for people:

a) where the complexity or intensity of their medical, nursing care or other care or the need for frequent not easily predictable interventions requires the regular (in the majority of cases this might be weekly or more frequent) supervision of a consultant, specialist nurse or other NHS member of the multidisciplinary team;

b) who require routinely the use of specialist health care equipment or treatments which require the supervision of specialist NHS staff; or

c) who have a rapidly degenerating or unstable condition which means that they will require specialist medical or nursing supervision.

2.9 The Department issued supplementary guidance in February 1996, which referred to the danger of eligibility criteria being over-restrictive. It specifically mentioned the risk of over- relying on the needs of a patient for specialist medical opinion when determining eligibility for continuing NHS funded care. It said that there would be a limited number of cases where the complexity or intensity of nursing or other clinical needs might mean that a patient was eligible for continuing care even though that patient no longer required medical supervision.

2.10 The next step on the history of the development of CHC was the seminal case of *R v. North and East Devon Health Authority ex-parte Pamela Coughlan* [2001] QB 213 in July 1999[8]. The Court of Appeal was required to consider whether the health authority had acted lawfully in seeking to close Mardon House and to transfer care responsibilities for the residents to the local authority. At first instance, Hidden J explained that the residents needed nursing services and that, in his view, these could only be provided by an NHS body. He said the provision of both general and specialist nursing services were "'health care' and can never be 'social care'. His view was that the health authority was wrong because:

> "both general and specialist nursing care remain the *sole responsibility* of the health authorities"

2.11 The Health Authority appealed and the Court of Appeal had to decide where the line was to be drawn between health and social care services. The Court of Appeal did not see the divide in such clear terms as the Judge at first instance. The conclusions of the Court of Appeal are worth setting out in full as follows:

[8] See http://www.bailii.org/ew/cases/EWCA/Civ/1999/1871.html

"(a) The Secretary of State can exclude some nursing services from the services provided by the NHS. Such services can then be provided as a social or care service rather than as a health service.

(b) The nursing services which can be so provided as part of the care services are limited to those which can legitimately be regarded as being provided in connection with accommodation which is being provided to the classes of persons referred to in section 21 of the 1948 Act who are in need of care and attention; in other words as part of a social services care package.

(c) The fact that the nursing services are to be provided as part of social services care and will have to be paid for by the person concerned, unless that person's resources mean that he or she will be exempt from having to pay for those services, does not prohibit the Secretary of State from deciding not to provide those services. The nursing services are part of the social services and are subject to the same regime for payment as other social services. Mr Gordon submitted that this is unfair. He pointed out that if a person receives comparable nursing care in a hospital or in a community setting, such as his or her home, it is free. The Royal Commission on Long Term Care, in its report, "With Respect to Old Age" (Cm 4192-I) (March 233 1999), chapter 6, pp 62 et seq, not surprisingly agrees with this assessment and makes recommendations to improve the situation. However, as long as the nursing care services are capable of being properly classified as part of the social services responsibilities, then, under the present legislation, that unfairness is part of the statutory scheme.

(d) The fact that some nursing services can be properly regarded as part of social services care, to be provided by the local authority, does not mean that all nursing services provided to those in the care of the local authority can be treated in this way. The scale and type of nursing required in an individual case may mean that it would not be appropriate to regard all or part of the nursing as being part of "the package of care" which can be provided by a local authority. There can be no precise legal line drawn between those nursing services which are and those which are not capable of being treated as included in such a package of care services.

(e) The distinction between those services which can and cannot be so provided is one of degree which in a borderline case will depend on a careful appraisal of the facts of the individual case. However, as a very general indication as to where the line is to be drawn, it can be said that if the nursing services are (i) merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide to the category of persons to whom section 21 of the 1948 Act refers and (ii) of a nature which it can be expected that an authority whose primary responsibility is

to provide social services can be expected to provide, then they can be provided under section 21. It will be appreciated that the first part of the test is focusing on the overall quantity of the services and the second part on the quality of the services provided.

(f) The fact that care services are provided on a means tested contribution basis does not prevent the Secretary of State declining to provide the nursing part of those services on the NHS. However, he can only decline if he has formed a judgment which is tenable and consistent with his long-term general duty to continue to promote a comprehensive free health service that it is not necessary to provide the services. He cannot decline simply because social services will fill the gap"

2.12 This Court of Appeal judgment appears to be the origin of the "*incidental or ancillary*" test concerning residential accommodation which defines the type of care placements that can properly be classified as being social care. This test continues to be part of the process of assessing eligibility to CHC today: see Regulation 21(7) of the 2012 Regulations. This part of the *Coughlan* case was primarily about whether a local authority was lawfully obliged to provide nursing services. It was not (at least at this stage of the argument) a case about whether the NHS was under a duty to fund accommodation and social care services. It thus left open the possibility of a gap between health and social care provision.

2.13 The next significant step was section 49 of the Health and Social Care Act 2001 ("**the 2001 Act**") which effectively prevented local authorities from employing registered nurses as part of the package of care provided at local authority care homes or funding care to be provided by nurses at homes run in the private sector. This legislation was, in part, a government response to the Royal Commission on Long Term Care chaired by Sir Stewart Sutherland ("**the Sutherland Report**"). The Sutherland Report had recommended that personal care for elderly people in need should be made available to everyone, subject to a needs assessment. It thus recommended that personal care for elderly people should be paid for from general taxation and that, for others, it should be subject to co-payment arrangements according to means. The then government were not prepared to accept the

recommendations (or pay the cost of this bold recommendation) but as a compromise it enacted section 49 of the 2001 Act. This provided:

> "(1) Nothing in the enactments relating to the provision of community care services shall authorise or require a local authority, in or in connection with the provision of any such services, to—
>
> (a) provide for any person, or
>
> (b) arrange for any person to be provided with,
>
> nursing care by a registered nurse.
>
> (2) In this section "nursing care by a registered nurse" means any services provided by a registered nurse and involving—
>
> (a) the provision of care, or
>
> (b) the planning, supervision or delegation of the provision of care,
>
> other than any services which, having regard to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse.

2.14 The broad effect of section 49 of the 2001 Act was thus to prevent local authorities from having either the legal power or legal duty to employ or pay for nursing services as part of their community care obligations. The idea was to ensure that, where the services of a nurse were required by a patient outside of a hospital environment, those services should be funded by the NHS and not by a local authority.

2.15 Following the *Coughlan* judgement the Department of Health released some fairly unhelpful Guidance "*Continuing Care: NHS and Local Council's Responsibilities HSC*

2001/015"[9]. This Guidance introduced a distinction between "continuing care" and "Continuing NHS health care" for the first time. It defined continuing care as follows:

> 'Continuing care' (or 'long term care') 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. It can be provided in a range of settings, from an NHS hospital, to a nursing home or residential home, and people's own homes"

In contrast, it defined "Continuing NHS Health care" as follows:

> "Continuing NHS health care' describes a package of care arranged and funded solely by the NHS. It does not include the provision by local councils of any social services"

2.16 The Guidance then recommended that local health authorities set their own eligibility criteria to determine which patients were and were not entitled to Continuing NHS Health care (i.e. a package of health and community care services care funded exclusively by the NHS). Annex C gave some guidance about what should be contained within local NHS policies. It said:

> "1. The eligibility criteria or application of rigorous time limits for the availability of services by a health authority should not require a local council to provide services beyond those they can provide under section 21 of the National Assistance Act (see point 20 of the guidance for the definition of nursing care used in the Coughlan judgement).
>
> 2. The nature or complexity or intensity or unpredictability of the individual's health care needs (and any combination of these needs) requires regular supervision by a member of the NHS multidisciplinary team, such as the consultant, palliative care, therapy or other NHS member of the team.
>
> 3. The individual's needs require the routine use of specialist health care equipment under supervision of NHS staff.

[9] See http://webarchive.nationalarchives.gov.uk/20120503185631/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4012280.pdf

> 4. The individual has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multidisciplinary team, such as the consultant, palliative care, therapy or other NHS member of the team.
>
> 5. The individual is in the final stages of a terminal illness and is likely to die in the near future.
>
> 6. A need for care or supervision from a registered nurse and/or a GP is not, by itself, sufficient reason to receive continuing NHS health care.
>
> 7. The location of care should not be the sole or main determinant of eligibility. Continuing NHS health care may be provided in an NHS hospital, a nursing home, hospice or the individual's own home.
>
> Guidance on free nursing care will include more details on determining registered nurse input to services in a nursing home, where the care package does not meet continuing NHS health care eligibility criteria"

2.17 This Guidance demonstrated the tensions in government which have always been present in CHC policy. There are 2 primary sets of tensions. First, there are tensions between health and social care organisations. A patient with serious disabilities represents a long-term resource commitment for the state. Thus working out which side of the NHS/social care line such a patient falls is important because both NHS and local budgets have been under immense pressure and will remain under pressure for the foreseeable future. Secondly there are tensions between patients (and their families) and the NHS. Patients naturally want to fall under NHS Continuing Care because this will result in the patient getting social care and accommodation which is free at the point of use. The practical consequence of "*going into [social] care*" is that many family homes have to be sold to pay care fees. Thus the entirely understandable aspiration of both the patient and their relatives that the home should be an asset to be passed to the next generation is thwarted. Whilst this is an entirely legitimate perspective, some of the mechanisms used by families to avoid the state getting their hands on the home may have less legitimacy.

From the NHS perspective, the expression "where there's a will, there's a relative" has come to the mind of many NHS officials struggling to define the boundary and trying to explain to an insistent relative why their elderly mother or father is not entitled to CHC. Those two sets of tensions – the NHS/LA tension and the NHS/patient and family tension – run through CHC policy like the word Brighton runs through a stick of seaside rock. There are always present, albeit often just below the surface.

2.18 In 2003 the Parliamentary and Health Service Ombudsman issued a special report *NHS funding for long term care* (February 2003, HC 399) which criticised both central government and individual NHS bodies in relation to their approach to eligibility for CHC, and upheld a large number of specific complaints from members of the public where a patient had been denied free NHS and social care. The Ombudsman reported on the 2001 Guidance in the following unflattering terms:

> "A pattern is emerging from the complaints I have seen of NHS bodies struggling, and sometimes failing, to conform to the law and central guidance on this issue, resulting in actual or potential injustice arising to frail elderly people and their relatives (paragraph 1).
>
> I do not underestimate the difficulty of setting fair, comprehensive and easily comprehensible criteria. The criteria have to be applied to people of all ages, with a wide range of physical, psychological and other difficulties. There are no obvious, simple, objective criteria that can be used. But that is all the more reason for the Department to take a strong lead in the matter: developing a very clear, well-defined national framework. One might have hoped that the comments made in the *Coughlan* case would have prompted the Department to tackle this issue. However, efforts since then seem to have focused mainly on policy about free nursing care. Authorities were left to take their own legal advice about their obligations to provide continuing NHS health care in the light of the *Coughlan* judgment. I have seen some of the advice provided, which was, perhaps inevitably, quite defensive in nature. The long awaited further guidance in June 2001 [HSC 2001/015] gives no clearer definition than previously of when continuing NHS health care should be provided: if anything it is weaker, since it simply lists factors authorities should 'bear in mind' and details to which they should 'pay attention' without saying how they should be taken into

> account. I have criticised some Authorities for having criteria which were out of line with previous guidance: except in extreme cases I fear I would find it even harder now to judge whether criteria were out of line with current guidance. Such an opaque system cannot be fair. (paragraph 31)"

2.19 Two significant and legitimate criticisms can be made of the PHSO report. First, it criticised variations between the polices adopted by different health authorities. That is a misguided criticism because the NHS has always been set up a national service with local decision makers. Whenever there are local decision makers, there will be differences between the decisions that are made. Hence, differences between services being made available in different areas are an inevitable consequence of the decision making system, not necessarily evidence that the system is failing. Secondly, it is arguable that the report only considered the perspective of prospective CHC patients and their families. It gave insufficient weight to the needs of other patients who were also seeking funding for NHS treatment out of the same limited budget. However the NHS was probably too timid to point out these errors and largely adopted a "*mea culpa*" approach.

2.20 The 2001 Guidance was also subsequently the subject of some pointed criticism by Mr Justice Charles in *R (on the application of Grogan) v Bexley NHS Care Trust & Ors* [2006] EWHC 44 (Admin)[10]. However the Judge in that case importantly noted at §37:

> ".. the divide between the duties relating to the provision of health services and social services is not between two duties that are enforceable by individuals. This is because the duties of the local authority are so enforceable but the relevant duties of the [Secretary of State] in respect of the NHS are "target duties"

The Judge also said at §39:

[10] See http://www.bailii.org/ew/cases/EWHC/Admin/2006/44.html

> "I accept as submitted on behalf of the [Secretary of State] that the extent of her duties to provide health services is governed by the health legislation and not by the limits of the duties of local authorities. Thus I accept that there is potential for a gap between what the [Secretary of State] (through the relevant health bodies) provides, or is under a duty to provide, as part of the NHS, and "health services" that could lawfully be supplied by local authorities"

The Judge complained that the 2001 Department of Health Guidance was "*far from being as clear as it might have been"* and concluded that it was partially to blame for the failure of local NHS bodies to adopt a consistent approach to eligibility for CHC. However, one significant feature of the *Grogan* case was that the local authority were not parties to the action and hence not represented at court. Thus, the court only had the perspectives of the patient, the Secretary of State and the NHS, but was not assisted by the perspective of the local authority.

2.21 The adoption of different eligibility criteria by different health authorities and the then newly emerging local commissioners, known as "primary care trusts" ("**PCTs**"), led to a plethora of complaints about a "post code lottery" around the entitlement of individual patients to CHC. Complaints about a postcode lottery are a standard of any debate on NHS services. Critics of decisions often affirm the benefits of "local decision making", assuming a local decision will be in their favour, but equally complain about decisions varying between localities when they go against them. A "postcode lottery" is, of course, the inevitable result of local decision making. However, the perceived unfairness of different CHC eligibility policies in different areas led the Department of Health to require CHC eligibility criteria to be set by Strategic Health Authorities ("**SHAs**") from 1 April 2004.

2.22 PCTs remained as the statutory decision makers to decide which patients were eligible for CHC but, in making this decision after 1 April 2004, PCTs were required to use the SHA eligibility criteria to determine eligibility for NHS Continuing Care. This change was aimed at delivering a greater level of consistent approach over the area of the SHA. At this stage, there were 10 (later 9) SHAs covering the whole of England.

However, there were still elements of post-code lottery in this system because the interpretation of the SHA criteria differed between different PCTs within the SHA area and, even if a patient was eligible, the package of care that an eligible patient received was determined by the policies of individual PCTs.

2.23 The 2001 Guidance introduced a further stage for patients, namely the SHA Review Panel. These panels were commonly referred to as "Appeal Panels" but they were not final decision makers. The panels reviewed cases and made "recommendations" back to the PCTs, but could not take their own decisions. However, few if any of the recommendations were not accepted by PCTs.

2.24 The adoption of SHA eligibility criteria and SHA appeal panels did not lead to a completely uniform approach across the country and hence complaints continued. The government responded by introducing national CHC criteria covering the whole of England. These were first adopted in the first National Framework for NHS Continuing Healthcare which was published in October 2007. The National Framework was updated in 2009 and was further updated in 2012. A new version of the National Framework has now been published. That will take effect from October 2018. A detailed description of the new National Framework will be provided in the next edition of this book.

2.25 The present position is thus that a person's eligibility for CHC is determined by applying rules in part 6 of the 2012 Regulations which, in turn, follows the decision making process set out in the 2012 version of the National Framework. The details of the eligibility decision making process are explained below. However, the package of services that an eligible patient receives is still governed by the policies of the local NHS commissioners, which is now the relevant CCG.

2.26 The present version of the National Framework has a "Part 2[11]" which consists of a series of Questions and Answers called "Practice Guidance". This part is a record of the accumulated guidance provided by Departmental officials to NHS bodies over the years. It is perhaps inevitable that there is not complete uniformity between the main section and of the Guidance and the "Practice Guidance". This leads to the unfortunate position that, in the case of disputes, both patients and NHS bodies can find parts of the Guidance to support their positions. Where such disputes arise, the court will have to interpret the Guidance in order to seek to draw out a consistent meaning. The proper interpretation of guidance is for the courts, not for a CCG or even NHS England: see *Tesco Stores Ltd v Dundee City Council (Scotland)* [2012] UKSC 13.

3 The legal basis for the provision of NHS Continuing Care.

3.1 The 1995 Guidance grappled with the problem as to when the NHS should provide a comprehensive package of health and social care services for a seriously ill patient, which was free at the point of use but was delivered outside of a hospital environment. That conundrum has remained the central issue for subsequent policy makers in this area. From a legal perspective, section 3 of the National Health Service Act 2006 ("**the NHS Act**") requires clinical commissioning groups, who are the statutory successors of PCTs, to make arrangements to provide the following services:

> "(1) "A clinical commissioning group must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the persons for whom it has responsibility:
>
> (a) hospital accommodation;

[11] Starting at page 50.

(b) other accommodation for the purpose of any service provided under this Act;

(c) medical, dental, nursing and ambulance services;

(d) such other facilities for the care of expectant and nursing mothers and young children as the group considers are appropriate as part of the health service;

(e) such facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness as the group considers are appropriate as part of the health service;

(f) such other services as are required for the diagnosis and treatment of illness"

3.2 NHS Continuing Healthcare ("CHC") involves the provision of a "package" of care and support to the meet the needs of someone who has a primary healthcare need. This can include medical care (i.e. the services of medical professionals plus drugs and other medical inventions). However, it can also include accommodation and social care in addition to medical care. The legal basis for the provision of such services is a combination of section 3(1)(c) (for medical and nursing services), section 3(1)(b) (for accommodation) and section 3(1)(e) (for social care and other services). In *R (Whapples) v Birmingham Crosscity Clinical Commissioning & Anor* [2015] EWCA Civ 435 the Court of Appeal found that the power to create the National Framework was contained in section 2 of the NHS Act.

3.3 The obligation to provide accommodation to CHC patients, when this is part of their overall needs, probably arises under section 3(1)(b) although a clear view on this is somewhat difficult as a result of the judgments in *Whapples* which specifically left the matter open. It appears reasonably clear that the duty to provide accommodation to a CHC patient outside a hospital arises when the patient has a "reasonable requirement" for accommodation for the purpose of any service

provided under the NHS Act. That raises the slightly difficult question as the meaning of the term "hospital" in the NHS Act. The word "hospital" is widely defined in section 275 of the NHS Act to include "*any institution for the reception and treatment of persons suffering from illness*". A care home can amount to a "hospital" where the resident requires and is provided with nursing services: see *Minister of Health v General Committee of the Royal Midland Counties Home for Incurables at Leamington Spa* [1954] 1 Ch 530, *Chief Adjudication Officer v White* (reported as *R(IS) 18/94*) and *Botchett v Chief Adjudication Officer* (reported as R(IS) 10/96. See also *R (DLA 2/06)* which explains the legislative history in some detail.

3.4 However, the obligation to provide accommodation will rarely, if ever, result in the NHS having a duty to provide "ordinary accommodation" to a patient outside of a care home environment. In *Whapples* the Court of Appeal said:

> "Read as a whole, the National Framework does not, in circumstances where a patient is receiving NHS continuing healthcare in his own home, generally contemplate that the NHS will be responsible for defraying the costs of that accommodation"

3.5 However, that case made it clear that, where a person needs accommodation which is different from the accommodation in which they are presently living in order to deliver health and social care services, a local authority may well have a duty to provide suitable accommodation to such a person under its community care powers. These powers were under section 21 of the National Assistance Act 1948 in *Whapples* and are now under the Care Act 2014 after 1 April 2015.

3.6 The extent of the NHS's obligation to provide "other services" under section 3(1)(e) is subject to the additional qualification that they are only such services as the CCG considers to be "*appropriate as part of the health service*". That clearly gives the CCG a wider discretion to determine the circumstances in which CHC services should and should not be provided to NHS patients. However, in exercising that discretion, the

CCG must follow the guidelines set out in the National Framework unless it has a good reason to depart from the guidance.

4 The decision making process to determine who is eligible for CHC?

4.1 From October 1st 2007, a National Framework is required to be used by local NHS decision makers to determine eligibility. The National Framework has been updated from time to time and the present version dates from November 2012[12]. The rules on CHC eligibility are now contained in the 2012 Regulations. Part 6 of the 2012 Regulations[13] sets out the tests to be applied by each CCG to determine whether a patient is eligible for CHC.

4.2 The CCG or NHS England decision making process to determine whether a patient is eligible for CHC ought to be completed and a decision made and communicated to the patient within a maximum of 28 days. Paragraph 95 of the National Framework sets out the timescales as follows:

> "The time that elapses between the Checklist (or, where no Checklist is used, other notification of potential eligibility) being received by the CCG and the funding decision being made should, in most cases, not exceed 28 days. In acute services, it may be appropriate for the process to take significantly less than 28 days if an individual is otherwise ready for discharge. The CCG can help manage this process by ensuring that potential NHS continuing healthcare eligibility is actively considered as a central part of the discharge planning process, and also by considering whether it would be appropriate to provide interim or other NHS-funded services, as set out in paragraph 65 above"

[12] See https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf The 2018 version of the National framework will come into force on 1 October 2018. This text does not cover the 2018 document.

[13] The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 SI 2996/2012 as amended by a series of subsequent amendment Regulations.

4.3 Regulation 20 transposes the definitions of "NHS continuing care" into statute for the first time. The definition is the same as in the National Framework, namely:

> "NHS Continuing Healthcare" means a package of care arranged and funded solely by the health service in England for a person aged 18 or over to meet physical or mental health needs which have arisen as a result of disability, accident or illness"

The word "care" is not defined in the Regulations or in the NHS Act and so the meaning of the services that can be provided as part of a package of "care" must be taken from the Guidance.

The duty to carry out assessments to inform eligibility decisions.

4.4 Regulation 21(1) of the 2012 Regulations provides:

> "A relevant body must take reasonable steps to ensure that an assessment of eligibility for NHS Continuing Healthcare is carried out in respect of a person for which that body has responsibility in all cases where it appears to that body that—
>
> (a) there may be a need for such care; or
>
> (b) an individual who is receiving NHS Continuing Healthcare may no longer be eligible for such care"

4.5 The 2012 Regulations thus impose a statutory duty on the CCG to take reasonable steps to carry out an assessment if the CCG comes under a legal duty to carry out the assessment if the CCG is aware of the existence of the individual and has information that "may" suggest a patient could become eligible for CHC or there has been a variation in the care services for a CHC eligible patient.

4.6 CCGs are not under an absolute duty to carry out a CHC assessment, but only to take "reasonable steps" to do so. In practice, the patient with capacity is required to give their consent to the CCG using the patient's records to carry out the assessment. If a patient who has capacity to give or refuse consent to medical treatment refuses to

give their consent, it will be practically impossible for the CCG to carry out any assessment. The National Framework Guidance at PG6 (page 58) does not deal satisfactorily with this point n suggesting that NHS bodies and local authorities should proactively seek to escalate cases where individuals with capacity refuse assessments. That comes close to an attempt to force NHS treatment on reluctant patients. The better view is that patients with capacity have an absolute right to refuse treatment for good reasons, bad reasons or no reasons: see *Re T (Adult: Refusal of Treatment)* [1993] Fam 95. Hence if a patient with capacity refuses to be assessed for CHC, that is a decision that the NHS commissioning body is required to accept. Thus the "reasonable steps" that a CCG is required to take in such cases may well be no steps at all.

4.7 Regulation 20(2) of the 2012 Regulations provides:

> "(2) For the purposes of this Part a relevant body has responsibility for a person if the body is responsible—
>
> (a) in the case of a CCG, by virtue of—
>
> (i) section 3(1A) of the 2006 Act, except where the person is a person for whom another CCG is responsible by virtue of paragraph 2(b), (d), (e) or (f) of Schedule 1 to these Regulations, or
>
> (ii) paragraph 2, other than paragraph 2(a), of Schedule 1 to these Regulations; or
>
> (b) in the case of the Board, by virtue of regulation 7 (secondary care services and community services: serving members of the armed forces and their families) or regulation 10 (services for prisoners and other detainees)"

4.8 Accordingly, NHS England only has duties to assess and make decisions about the eligibility of patients for CHC for serving members of the armed forces and their families and for prisoners and other detainees. The responsibility for conducting

assessments and making eligibility decisions lies with CCGs in all other cases, even if the main services that the patient needs are specialised services and thus fall to be commissioned by NHS England. This means the vast majority of CHC eligibility decisions are made by CCGs and not by NHS England. The decision maker for CHC eligibility is thus referred to in this chapter as "the CCG". However the same decision making processes are required to be followed by NHS England in the limited number of cases where NHS England is the "relevant body" under the 2012 Regulations[14].

4.9 The information which can lead a CCG or NHS England to have the assessment duty can come from any source including a local authority, provided there is enough information to lead the CCG to believe that the patient may have need for CHC care. The duty to carry out a CHC assessment can thus arise whether there is a request by the patient or not. The wording of the duty is substantially the same as the duty on a local authority to carry out an assessment of an individual's entitlement to community care services under section 9 of the Care Act 2014 (formerly 47 of the NHS and Community Care Act 1990). The case law suggests that there is a low threshold before the duty to carry out an assessment arises (see *R (Pinfold) v Bristol Council*). All that is needed to trigger a duty to carry out an assessment is for the CCG to have sufficient information that a patient "may" be eligible for CHC.

4.10 There is an unresolved question as to whether an NHS patient who is in hospital and will remain in hospital for the foreseeable future is a person who comes within Regulation 21(2)(a) of the 2012 Regulations (i.e. is a person where there may be a need for CHC care). CHC is defined as a "*package of care arranged and funded solely by the health service*". It is not wholly clear from this wording whether someone who is in long term care in a hospital could be a person who is in receipt of a "package" of NHS funded care. Paragraph 13 of the National Framework provides:

[14] NHS England has no published procedures for making its own decisions concerning CHC eligibility, but is required to follow the decision making processes under the National Framework.

> "Eligibility for NHS continuing healthcare places no limits on the settings in which the package of support can be offered or on the type of service delivery"

4.11 This wording suggests that a CHC eligible patient could have their needs met within an NHS hospital and thus suggests that a long term NHS patient may well be entitled to an assessment and eligibility decision. However, the better view is probably that the word "package" of care is looking to arrangements for care outside of a hospital setting, and that a patient who will be remaining in hospital for the foreseeable future is not entitled to demand a CHC assessment. However if there is any real possibility that such a patient should continue to receive care in a hospital or community setting, the patient will be someone who "may" have an entitlement to CHC and thus should be subject to the assessment process.

Hospital discharge cases.

4.12 Patients are often assessed for their eligibility for CHC at the point that they are ready to be discharged from hospital. Paragraphs 62 to 67 of the National Framework set out the approach to be taken in such cases as follows:

> **"24 Hospital Discharge**
>
> 62. In a hospital setting, before an NHS trust, NHS foundation trust or other provider organisation gives notice of an individual's case to an LA, in accordance with section 2(2) of the Community Care (Delayed Discharges etc.) Act 2003, it must take reasonable steps to ensure that an assessment for NHS continuing healthcare is carried out in all cases where it appears to the body that the patient may have a need for such care. This should be in consultation, as appropriate, with the relevant LA.
>
> 63. CCGs should ensure that local protocols are developed between themselves, other NHS bodies, LAs and other relevant partners. These should set out each organisation's role and how responsibilities are to be exercised in relation to delayed discharge and NHS continuing healthcare, including responsibilities with regard to the decision-making on eligibility. There should be processes in place to identify those individuals for whom it is appropriate to use the Checklist and, where the Checklist indicates that they may have needs that would make them eligible for NHS continuing healthcare, for full assessment of eligibility to then take place.

64. Assessment of eligibility for NHS continuing healthcare can take place in either hospital or non-hospital settings. It should always be borne in mind that assessment of eligibility that takes place in an acute hospital may not always reflect an individual's capacity to maximise their potential. This could be because, with appropriate support, that individual has the potential to recover further in the near future. It could also be because it is difficult to make an accurate assessment of an individual's needs while they are in an acute services environment. Anyone who carries out an assessment of eligibility for NHS continuing healthcare should always consider whether there is further potential for rehabilitation and for independence to be regained, and how the outcome of any treatment or medication may affect ongoing needs.

65. In order to address this issue and ensure that unnecessary stays on acute wards are avoided, there should be consideration of whether the provision of further NHS-funded services is appropriate. This might include therapy and/or rehabilitation, if that could make a difference to the potential of the individual in the following few months. It might also include intermediate care or an interim package of support in an individual's own home or in a care home. In such situations, assessment of eligibility for NHS continuing healthcare should usually be deferred until an accurate assessment of future needs can be made. The interim services (or appropriate alternative interim services if needs change) should continue in place until the determination of eligibility for NHS continuing healthcare has taken place. There must be no gap in the provision of appropriate support to meet the individual's needs.

66. Where NHS-funded care, other than on an acute ward, is the next appropriate step after hospital treatment, this does not trigger the responsibilities under the Community Care (Delayed Discharges etc.) Act 2003.

67. Whenever an individual outside a hospital setting is having their health or social needs assessed or reviewed by a CCG or an LA, consideration should always be given to whether their needs suggest that it might be appropriate to use the Checklist (see below) to identify whether or not there is potential eligibility for NHS continuing healthcare"

4.13 The above Guidance does not appear controversial. However there is a chart at page 23 of the National Framework which raises some difficult legal issues. It seeks to explain how a CCG should respond where a patient is identified as "*possibly eligible for NHS CHC*". It suggests that, unless a patient is on the "fast-track" because the

patient has a rapidly deteriorating condition, the first question CCG staff should ask themselves is:

> "Could NHS Services enable further improvements in health/functioning that might alter outcome of eligibility decision"

4.14 The Flow Chart suggests that, if the answer to that question is "Yes", the NHS rehabilitation/reablement or other services should be provided. That part of the guidance is uncontroversial. However it suggests that, in such a case, the CCG should not, at that stage, undertake the assessment and eligibility decision making process. This approach is supported in the Guidance by paragraph 65 which provides:

> "In order to address this issue and ensure that unnecessary stays on acute wards are avoided, there should be consideration of whether the provision of further NHS-funded services is appropriate. This might include therapy and/or rehabilitation, if that could make a difference to the potential of the individual in the following few months. It might also include intermediate care or an interim package of support in an individual's own home or in a care home. In such situations, assessment of eligibility for NHS continuing healthcare should usually be deferred until an accurate assessment of future needs can be made. The interim services (or appropriate alternative interim services if needs change) should continue in place until the determination of eligibility for NHS continuing healthcare has taken place. There must be no gap in the provision of appropriate support to meet the individual's needs"

4.15 Whilst this is Guidance produced by the Secretary of State to which CCGs have a legal duty to consider, where there is contradiction between the Guidance and a statutory duty imposed by Regulations, the statutory duty must take precedence. The circumstances envisaged above relate to a person who, by definition, "may" have a need for CHC and thus the CCG has a statutory duty to carry out an assessment and decision making process. The possibility that an individual patient, who may well have a "primary health need" at that point, may (or may not) cease to be have such a need after being in receipt of rehabilitation services for some months cannot relieve the CCG of undertaking the assessment duty under Regulation 21 of the 2012

Regulations. If the patient is due to leave hospital and, at that point, may have a primary health need, the CCG is under a legal duty to carry out an assessment to determine whether the patient is eligible for CHC[15].

4.16 The error in this Guidance can be illustrated by considering the circumstances of a patient who is discharged from hospital to a care home in order to receive a course of therapy and rehabilitation in accordance with the terms of this paragraph. The package of medical therapy and rehabilitation services will, of course, be funded by the CCG. However, a question may arise as to whether the care home accommodation and social care fees should be funded by the NHS or by social care (which, for a patient with means, will effectively mean that the patient is funding the care home fees himself or herself). Care home fees are generally only paid for patients who have been determined to be eligible for CHC. In all other cases, the care home services are treated as being social care services which may (depending on the needs of the service user) be social care services that a local authority may be required to fund under the Care Act 2014. However, Care Act services are means tested and thus the service in these circumstances use may well end up funding their own services even though a CHC assessment would show that, at that time, the patient is eligible for NHS funded social care and accommodation. Thus CCGs should be extremely wary about seeking to delay CHC assessments in an attempt to transfer the costs of accommodation and social care to local authorities whilst patients are undertaking medical therapy and rehabilitation services. Patients and their relatives may well wish to challenge any failure by a CCG to undertake a full CHC assessment and decision making process in such circumstances.

4.17 The potential problems with this Guidance are, to some extent, ameliorated by PG14[16] which suggests that intermediate care or the type described should be funded by the NHS. It provides:

[15] See PG18 at page 66 of the National Framework.
[16] See page 64/5 of the National Framework.

"PG 14 How does NHS continuing healthcare link with intermediate care?

14.1 Intermediate care is aimed at people who would otherwise face unnecessarily prolonged hospital stays or inappropriate admission to acute or longer-term in-patient care or long-term residential care. It should form part of a pathway of support. For example, intermediate care may be appropriately used where a person has received other residential rehabilitation support following a hospital admission and, although having improved, continues to need support for a period prior to returning to their own home. It should also be used where a person is at risk of entering a care home and requires their needs to be assessed in a non-acute setting with rehabilitation support provided where needed. This is irrespective of current or potential future funding streams, but is clearly important in the context of consideration for NHS continuing healthcare.

14.2 CCGs should have regard to the most recent guidance in relation to Intermediate Care.

14.3 Individuals should not be transferred directly to long-term residential care from an acute hospital ward unless there are exceptional circumstances. Such circumstances might include:

> a) those who have already completed a period of specialist rehabilitation, such as in a stroke unit
>
> b) those who have had previous failed attempts at being supported at home (with or without intermediate care support)
>
> c) those for whom the professional judgement is that a period in residential intermediate care followed by another move is likely to be unduly distressing.

14.4 The guidance referred to above sets out what intermediate care should look like as well as how to commission it, with an emphasis on partnership working. CCGs should seek to ensure that this pathway is followed prior to any long-term placement apart from exceptional circumstances"

Carry out assessments for patients who are due to leave hospital.

4.18 The duty in the 2012 Regulations to carry out a CHC assessment can arise where a patient is being discharged from hospital if, at the point of discharge, the CCG believes that the patient may qualify for CHC. There is also a duty on the CCG and a Hospital Trust to consider whether a patient qualifies for CHC when discharging a patient from hospital if there is a delayed discharge. There is also duty to carry out an assessment if a patient "may no longer be eligible for such care". Hence if a CCG has information that suggests that a CHC eligible patient is no longer eligible for CHC, the CCG has a duty to carry out an assessment to determine the true position.

4.19 Further Guidance on assessing CHC eligibility at the hospital discharge point is provided at PG13 which provides:

> **"PG 13 How does NHS continuing healthcare fit with hospital discharge procedures?**
>
> 13.1 Arrangements for applying the Framework should form an integral part of local hospital discharge policies, and should be implemented in such a way that delays are minimised. Timely assessments will prevent whole system delays within the acute hospital sector. LAs, CCGs and other NHS bodies providing hospital services should ensure that there is clarity in local discharge protocols and pathways about how NHS continuing healthcare fits into these processes, and what their respective responsibilities are.
>
> 13.2 CCGs should ensure that discharge policies with providers who are not NHS trusts are clear. Where appropriate, the CCG may wish to make provisions in its contract with the provider.
>
> 13.3 The 'delayed discharges' procedures (such as the issuing of section 2 and section 5 notices under the Community Care (Delayed Discharges etc.) Act 2003 as amended) are not triggered until the NHS trust or NHS foundation trust are satisfied that the relevant individual is not entitled to NHS continuing healthcare.
>
> 13.4 Where it appears to an NHS trust or NHS foundation trust that a person planned to be discharged from hospital may have a need for NHS continuing healthcare, a decision on eligibility should be made prior to notices being issued under delayed discharges legislation unless alternative NHS-funded services are provided.

13.5 It is preferable for eligibility for NHS continuing healthcare to be considered after discharge from hospital when the person's long-term needs are clearer, and for NHS-funded services to be provided in the interim. This might include therapy and/or rehabilitation, if that could make a difference to the potential further recovery of the individual in the following few months. It might also include intermediate care or an interim package of support in an individual's own home or in a care home. Where a person is discharged from hospital with such interim services in place delayed discharges legislation does not apply.

13.6 Social care practitioners should work jointly with NHS staff throughout the NHS continuing healthcare eligibility process, and should be involved as part of the MDT wherever practicable. Therefore, where the LA receives a referral for involvement in the MDT process for NHS continuing healthcare they should respond positively and promptly. The LA should usually be represented on the MDT completing the NHS continuing healthcare eligibility process. This means that, in most cases, the key assessment information needed for LA support is already available if the delayed discharge process is triggered subsequently. Therefore, where a person is found to be ineligible for NHS continuing healthcare and delayed discharge notices are then issued, the LA should be in a position to respond and action their responsibilities within a short timeframe.

13.7 CCGs and LAs could consider developing an agreed format for the NHS continuing healthcare multidisciplinary assessment that is also suitable for use as a community care assessment if the person is found ineligible for NHS continuing healthcare and delayed discharge processes are triggered.

13.8 In summary, CCGs should have appropriate processes and pathways in place to ensure that, where an individual may have a need for support after hospital discharge, one of the following scenarios will apply:

a) prior to completing a Checklist in hospital a decision is made to provide interim NHS-funded services to support the individual after discharge (in which case the delayed discharge provisions would not be triggered). In such a case, before the interim NHS-funded services come to an end, consideration of NHS continuing healthcare eligibility should take place through use of the Checklist and, where appropriate, the full MDT process using the DST;

b) a Checklist is completed which indicates the person may have a need for NHS continuing healthcare and interim NHS-funded services are put in place to support the

individual after discharge until a full MDT NHS continuing healthcare assessment is completed (in which case the delayed discharge provisions would not be triggered); or

c) a Checklist is completed which indicates the person may have a need for NHS continuing healthcare and a full MDT NHS continuing healthcare assessment takes place before discharge. If this results in eligibility for NHS continuing healthcare then the delayed discharge procedures do not apply as the NHS continues to have responsibility for the individual's care; or

d) a Checklist is completed which indicates the person may have a need for NHS continuing healthcare and a full MDT NHS continuing healthcare assessment takes place before discharge. If this does not result in eligibility for NHS continuing healthcare then the appropriate delayed discharge notices should be issued; or

e) a Checklist is completed before discharge which does not indicate the person may have a need for NHS continuing healthcare in which case the appropriate delayed discharges notices should be issued.

If a local area does not use the Checklist either generally or in individual cases then a full MDT NHS continuing healthcare assessment should take place before delayed discharge notices are issued"

4.20 The procedures under the Community Care (Delayed Discharges etc.) Act 2003 ("the 2003 Act") are mandatory and the Act remains in force. Many NHS bodies and local authorities have elected not to use the provisions of the 2003 Act despite its mandatory nature but, as a matter of law, NHS bodies are required to do so.

The CHC Checklist as an initial screening tool.

4.21 If the CCG has a legal duty to conduct a CHC assessment, the first step is often to use the CHC Checklist as an initial screening tool to screen out patients who are clearly not eligible for CHC (although there is no absolute legal duty to do so). Regulation 21(4) provides:

"If a relevant body wishes to use an initial screening process to decide whether to undertake an assessment of a person's eligibility for NHS Continuing Healthcare it must—

(a) complete and use the NHS Continuing Healthcare Checklist issued by the Secretary of State and dated 28th November 2012(11) to inform that decision;

(b) inform that person (or someone lawfully acting on that person's behalf) in writing of the decision as to whether to carry out an assessment of that person's eligibility for NHS Continuing Healthcare; and

(c) make a record of that decision"

4.22 The National Framework suggests that the Checklist procedure should be used as a first step in most cases. The procedure can be conducted by a nurse, doctor, social worker or other qualified healthcare professional[17]. The purpose of the checklist is to help practitioners identify people who need a full assessment for NHS continuing healthcare but who may not have sufficient needs to justify a full assessment. The form that should be completed goes through the care domains set out in the full assessment process and is attached to the Checklist document. Completion of the Checklist fulfils the duty in Regulation 21(4) of the 2012 Regulations to make a record of the decision. If a decision is made that a person is not CHC eligible after following the Checklist procedure, that is a sound basis for a CCG concluding that the person is not eligible for CHC

4.23 The CHC Checklist requires the multi-disciplinary team to assess whether the individual meets or exceeds the described need across 11 Care Domains (Column A) or is Borderline (Column B). A full consideration of eligibility is required if there are:

- two or more ticks in column A.
- five or more ticks in column B; or one tick in A and four in B.
- one tick in column A in one of the boxes marked with an asterisk (i.e., the domains which carry a priority level in the Decision Support Tool), with any number of ticks in the other two columns.

4.24 There may be special circumstances where a full consideration for NHS Continuing Healthcare is necessary even though the individual does not appear to meet the indicated threshold. If the patient does not pass the above tests then the CCG can be confident that the patient does not qualify for fully funded CHC. However, getting through the initial screening tool does not mean that a patient will qualify for fully funded CHC. There are many patients who will get through the initial screening but will not be entitled to fully funded CHC.

4.25 The form to be completed as part of the initial screening tool contains a section where the healthcare worker who completes the forms records their reasons for or against a full assessment. Completing the form with reasons is a legal requirement under the Regulations.

4.26 The Guidance PG22[18] explains what should happen once the Checklist has been completed. It provides:

> **"PG 22What should happen once the Checklist has been completed?**
>
> 22.1 If full consideration for NHS continuing healthcare is required the Checklist should be sent to the CCG where the individual's GP is registered unless alternative arrangements have been made by the CCG. If the individual does not have a GP, the responsible CCG should be identified using the approaches set out in the 'Who Pays' guidance. Checklists should be sent in the fastest, but most appropriate, secure way, which could include e-mail (if secure) or fax. The use of either internal or external postal systems can delay the receipt of the Checklist and should only be used if no other referral mechanism is available. Each CCG should have appropriate secure arrangements for the receipt of Checklists and these should be publicised to all relevant partners. The CCG will then arrange for a case coordinator to be appointed who will ensure that an MDT (including those currently treating or supporting the individual) carries out an assessment and uses this to complete a DST.

[17] See PG17 at page 66 of the National Framework.
[18] See pages 68/9 of the National Framework.

22.2 CCGs have the responsibility for ensuring that arrangements are in place so that individuals who are screened out at the Checklist stage are informed of the outcome, are given a copy of the Checklist, are given details of how to seek a review of the outcome by the CCG and are offered the opportunity for their case to be referred to the LA for consideration for social care support. This could be delegated by agreement to other organisations that have staff completing Checklists but CCGs have the ultimate responsibility.

22.3 Where a Checklist indicates that a referral for consideration for NHS continuing healthcare is not necessary, it is good practice for the Checklist to still be sent to the relevant CCG for information, as the individual may wish to request the CCG to reconsider the decision and the CCG will need a copy of the Checklist in order to do this"

The full assessment process.

4.27 Regulation 21(5) of the 2012 Regulations describes the process a CCG must follow when undertaking the full CHC assessment process. It provides:

"When carrying out an assessment of eligibility for NHS Continuing Healthcare, a relevant body must ensure that—

(a) a multi-disciplinary team—

(i) undertakes an assessment of needs, or has undertaken an assessment of needs, that is an accurate reflection of that person's needs at the date of the assessment of eligibility for NHS Continuing Healthcare, and

(ii) uses that assessment of needs to complete the Decision Support Tool for NHS Continuing Healthcare issued by the Secretary of State and dated 28th November 2012; and

(b) the relevant body makes a decision as to whether that person has a primary health need in accordance with paragraph (7), using the completed Decision Support Tool to inform that decision"

4.28 The Guidance recommends each CCG to appoint an NHS continuing healthcare co-ordinator whose role is to manage the process from the point that a full assessment

has been commenced through to the delivery of the final package. The details of this role are set out as follows at PG26[19]:

"PG 26 What is the role of the NHS continuing healthcare coordinator?

26.1 Once an individual has been referred for full assessment for NHS continuing healthcare, the CCG has the responsibility for coordinating the whole process until the eligibility decision is made. The CCG should identify an individual or individuals to carry out the coordination role. Whilst this is likely to be a CCG staff member, it could (by agreement) be a staff member from another organisation such as the LA, an NHS Trust or independent sector organisation. This could be part of a wider inter-agency agreement, or could be negotiated in specific cases due to the skills or responsibilities that the practitioner(s) have in relation to a client group or individual.

26.2 The coordination role includes:

a) receiving and acting upon a referral for assessment of eligibility for NHS continuing healthcare, ensuring appropriate consent has been given

b) identifying and securing the involvement of the MDT which will assess the individual's needs and will then use this information to complete the DST. The MDT should comprise health and social care staff presently or recently involved in assessing, reviewing, treating or supporting the individual

c) supporting MDT members to understand the role they will need to undertake in participating in a multidisciplinary assessment and completing the DST

d) helping MDT members to identify whether they will need to undertake an updated or specialist assessment to inform completion of the multidisciplinary assessment

e) supporting the person (and those who may be representing them) to play a full role in the eligibility consideration process, including ensuring that they understand the process, they have access to advocacy or other support where required, and organising the overall process in a manner that maximises their ability to participate

[19] See pages 70ff of the National Framework

f) ensuring that there is a clear timetable for the decision-making process, having regard to the expectation that decisions should usually be made within 28 days of the Checklist being received

g) ensuring that the assessment and DST processes are completed in accordance with the requirements in the Framework and relevant Responsibilities Directions

h) acting as an impartial resource to the MDT and the individual on any policy or procedure questions that arise

i) ensuring that the MDT's recommendation on eligibility is sent for approval through the relevant local decision-making processes in a timely manner

j) where local arrangements place the responsibility for informing the individual of the eligibility decision within the role of the coordinator, ensuring that this happens in a timely manner and in accordance with the requirements of the Framework.

26.3 Care should be taken by CCGs to ensure an appropriate separation between the coordinator role and those responsible for making a final decision on eligibility for NHS continuing healthcare.

Keeping the individual informed

26.4 Individuals should be kept fully informed throughout the process. The coordinator should ensure that this takes place, including:

- explaining timescales and key milestones
- making the person aware of other individuals likely to be involved
- informing them of any potential delays
- providing the individual with a key contact person and ensuring a clear channel of communication between them and the MDT
- helping the individual to understand the eligibility process as it progresses. In addition to the national public information leaflet it may be helpful to provide a

locally produced information leaflet explaining local processes and giving key contact numbers

• keeping family members appropriately informed, including where the individual indicates that s/he wishes this to take place and where family members will be involved in providing support to the individual and so need to be involved in agreeing their role"

4.29 Where a full CHC assessment is needed, the 2012 Regulations require an assessment by a multi-disciplinary team ("**MDT**"). There are a number of points to note. First, an MDT is defined in the Regulation 21(13) to mean a team consisting of either:

"(a) two professionals who are from different healthcare professions, or

(b) one professional who is from a healthcare profession and one person who is responsible for assessing persons for community care services under section 9 of the Care Act 2014 (assessment of an adult's needs for care and support)"

It is probably best practice to include a professional with a social care background as part of the MDT where it is clinically appropriate to do so, but it is lawful to have an MDT with two different healthcare professionals[20].

4.30 The role of the MDT is to carry out the assessment. However the MDT is not the final decision making body as to whether a patient qualifies for CHC. The MDT's role is to complete the assessment process and to provide the information to the CCG, and thus support the CCG decision maker to decide whether the patient is eligible for CHC. Membership of the MDT should be recorded with a full record is made of the conclusions of the MDT and the reasons for any recommendations that are put forward by the MDT.

[20] See PG30 at page 74 of the National Framework.

4.31 The MDT is required to meet and make decisions using the Decision Support Tool ("**DST**")[21]. The Guidance strongly advises against a "virtual" meeting or the members of the MDT filling in the forms separately without meeting. It provides[22]:

> **"PG 31 What happens if the coordinator is unable to engage relevant professionals to attend an MDT meeting?**
>
> 31.1 CCGs should not make decisions on eligibility in the absence of an MDT recommendation, unless exceptional circumstances require an urgent decision to be made.
>
> 31.2 Apart from ensuring that all the relevant information is collated, it is crucial to have a genuine and meaningful multidisciplinary discussion about the correct recommendation to be made. This should normally involve a face-to-face MDT meeting (including the individual and/or their representative). If a situation arises where a relevant professional is unable or unwilling to attend an MDT meeting every possible effort should be made to ensure their input to the process in another way, such as participating in the MDT meeting as a teleconference call. Where this is not possible then submission of a written assessment or other documentation of views could be used but this should be the least favoured option. Where professionals use this route, the CCG should explain to them that, whilst their views will be taken into account, the eligibility recommendation will by necessity be made by MDT members physically present or participating by teleconference.
>
> Care should be taken to ensure that alternative approaches for MDT participation still enable the individual being assessed to fully participate in the process.
>
> 31.3 If, even after having followed the above processes, there are still difficulties with the participation of, or obtaining assessment information from, a specific professional, CCGs should consider (in liaison with the individual) whether they have sufficient wider assessment information to reach a full picture of the individual's needs, having regard to the minimum MDT membership set out above. CCGs should record the attempts to secure participation.
>
> 31.4 In order to ensure effective MDT decision-making, CCGs should:

[21] The present version of the Decision Support Tool is dated June 2016 and is available at https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

[22] See page 75 of the National Framework.

a) have arrangements in place for coordinators to obtain senior support to secure participation of other practitioners where necessary

b) consider agreeing protocols on MDT participation with organisations that frequently have staff who participate in MDTs"

4.32 In practice this means that the multi-disciplinary team needs to ensure meet in person and ensure that the paperwork is completed for each of the Care Domains after a detailed discussion which seeks to reconcile any conflicting views. That involves an assessment of the level of need for each of the domains before a decision can be reached on CHC eligibility. The National Framework[23] contains the following Guidance about the MDT assessment:

"PG 28 What are the elements of a good multidisciplinary assessment?

28.1 Assessment in this context is essentially the process of gathering relevant, accurate and up-to-date information about an individual's health and social care needs, and applying professional judgement to decide what this information signifies in relation to those needs. Both information and judgement are required. An assessment that simply gathers information will not provide the rationale for any consequent decision; an assessment that simply provides a judgement without the necessary information will not provide the evidence for any consequent decision. Assessment documentation should be obtained from any professional involved in the individual's care and should be clear, well recorded, factually accurate, up to date, signed and dated. As a minimum a good quality multidisciplinary assessment of an individual's health and social care needs will be:

- preceded by informed consent or an appropriate 'best interests' decision as discussed in paragraph 50 of the National Framework

- proportionate to the situation, i.e. in sufficient depth to enable well-informed judgements to be made but not collecting extraneous information which is unnecessary to these judgements. If appropriate this may simply entail updating existing assessments

[23] See pages 70 to 72.

- person-centred, making sure that the individual and their representative(s) are fully involved, that their views and aspirations are reflected and that their abilities as well as their difficulties are considered

- informed by information from those directly caring for the individual (whether paid or unpaid)

- holistic, looking at the range of their needs from different professional and personal viewpoints, and considering how different needs interact

- taking into account differing professional views and reaching a commonly agreed conclusion

- considerate of the impact of the individual's needs on others

- focused on improved outcomes for the individual

- evidence-based – providing objective evidence for any subjective judgements made

- clear about needs requiring support in order to inform the commissioning of an appropriate care package

- clear about the degree and nature of any risks to the individual (or others), the individual's view on these, and how best to manage the risks.

28.2 Local assessment arrangements and processes differ around the country, though a number of models have formed the basis for assessment and care and support planning processes including the Single Assessment Process for older people, the Care Programme Approach33 and the Common Assessment Framework. Person-centred plans (which were originally developed for use by people with learning disabilities, but which can be used by anyone – and are increasingly being used more widely) are not assessments. Rather, they represent the individual's own view of their desired outcomes and support needs. As such, they can offer key evidence to be considered when completing both the assessment and the DST. Health action plans and health checks can also provide useful evidence.

28.3 Effective assessment processes and documentation are key to making swift decisions on eligibility for NHS continuing healthcare and for commissioning the right

care package at the right time and in the right place, so that the individual can move to their preferred place of choice as quickly and safely as possible.

28.4 CCGs and LAs should consider agreeing joint models of assessment documentation and having regular training or awareness events to support them"

4.33 The question as to which sources of information should be accessed by the MDT when undertaking the DST process will, of course, depend on the circumstances of an individual case. However PG29 of the National Framework suggests the following sources:

"PG 29 Potential Sources of Information/Evidence (not an exhaustive list):

- Health needs assessment
- Community care assessment
- Nursing assessment
- Individual's own views of their needs and desired outcomes
- Person-centred plan
- Carer's views
- Physiotherapy assessment
- Behavioural assessment
- Speech and Language Therapy (SALT) assessment
- Occupational Therapy assessment
- Care home/home support records
- Current care plan
- 24-hour/48-hour diary indicating needs and interventions (may need to be 'good day' and 'bad day' if fluctuating needs)
- GP information
- Specialist medical/nursing assessments (e.g. tissue viability nurse, respiratory nurse, dementia nurse, etc.)
- Falls risk assessment
- Standard scales (such as the Waterlow score)
- Psychiatric/community psychiatric nurse assessments"

4.34 An assessment which was completed without making reference to one or more significant sources of clinical information may well be unlawful unless the departure from the above guidance can be justified on the facts of an individual case.

4.35 One of the key elements in the CHC process is to attempt to secure consistency of decision making across a CCG and between CCGs. The variations between areas led to complaints of a "post-code lottery" around CHC. Discrepancies between decisions made by different NHS bodies was one of the primary criticisms of the 2003 PHSO Report and a concern for uniformity across the English NHS was, in part, a driver behind the creation of the National Framework. However the assessment process involves an element of professional judgment and thus an element of variation is inevitable. The Guidance contains the following passages which are aimed at keeping variations to a minimum:

> **"PG 33 What process should be used by MDTs to ensure consistency when completing the DST?**
>
> 33.1 Whilst local conditions and therefore local processes will vary, the following elements are recommended as being core to achieving consistency:
>
>> a) The coordinator should gather as much information as possible from professionals involved prior to the MDT meeting taking place, including agreeing where any new/updated specialist assessments are required prior to the meeting.
>>
>> b) The coordinator (or someone nominated by them) should explain the role of the MDT to the individual in advance of the meeting, together with details of the ways that the individual can participate. Where an individual requests copies of the documentation to be used this should be supplied.
>>
>> c) Information from the process above and any additional evidence should be discussed within the MDT meeting to ensure common agreement on individual needs. Where copies of assessments are circulated to MDT members at the meeting, copies should also be made available to the individual if they are present.
>>
>> d) Relevant evidence (and sources) should be recorded in the text boxes preceding each of the domain levels within the DST and this information should be used to identify the level of need within that domain, having regard to the user notes of the DST.

e) Depending upon local arrangements the MDT members may decide to reach the final recommendation on eligibility after the individual and their representative have left the meeting. However, the above gives clear expectations on their involvement in the wider process. If the MDT is to reach its final recommendation privately it is best practice to give the individual/representative an opportunity before they leave the meeting to state their views.

f) Having completed the care domains, the MDT should consider what this information signifies in terms of the nature, complexity, intensity and unpredictability of the individual's needs. It should then agree and record its recommendation, based on these concepts, providing a rationale which explains why the individual does or does not have a primary health need. It is important that MDT members approach the completion of the DST objectively without any preconceptions that specific conditions or diagnoses do or do not indicate eligibility or fit a particular domain level without reference to the actual needs of the individual (see below for more detail on recommendations).

g) The recommendation should then be presented to the CCG, who should accept this, except in exceptional circumstances. These circumstances could for example include insufficient evidence to make a recommendation or incomplete domains.

h) If the CCG, exceptionally, does not accept the MDT recommendation (see PG41 for circumstances when this can happen) it should refer the DST back to the MDT identifying the issues to be addressed. Once this has been completed the DST should be re-presented to the CCG who should accept the recommendation (except in exceptional circumstances).

i) The decision should be communicated in writing as soon as possible in an accessible format and language to the individual or their representative so that it is meaningful to them. They should also be sent a copy of the DST and information on how to ask for a review of the decision if the individual is dissatisfied with the outcome.

This whole process should usually be completed within 28 (calendar) days. This timescale is measured from the date the CCG receives the completed Checklist indicating the need for full consideration of eligibility (or receives a referral for full consideration in some other acceptable format) to the date that the eligibility decision

is made. However, wherever practicable, the process should be completed in a shorter time than this"

4.36 One of the key issues in practice is assessing the level of a "need" with the DST demonstrated by a patient if medical and social care interventions mean that the need is being effectively managed. The DST provides at paragraph 28:

"Needs should not be marginalised because they are successfully managed. Well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need will this have a bearing on NHS continuing healthcare eligibility. However, there are different ways of reflecting this principle when completing the DST. For example, where psychological or similar interventions are successfully addressing behavioural issues, consideration should be given as to the present-day need if that support were withdrawn or no longer available and this should be reflected in the Behaviour domain"

4.37 Thus a well-managed need remains as a "need" for the purposes of the assessment process. Further guidance on this tricky area is provided in PG11[24] which provides:

PG 11 How should the well-managed need principle be applied?

11.1 This Framework provides that the decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. The DST user notes provide additional guidance on the application of this principle at paragraphs 27 – 29. An example of this might occur in the context of the behaviour domain where an individual's support plan includes support/interventions to manage challenging behaviour, which is successful in that there are no recorded incidents which indicate a risk to themselves, others or property. In this situation, the individual may have needs that are well-managed and if so, these should be recorded and taken into account in the eligibility decision. In applying the principle of well-managed need, consideration should be given to the fact that specialist care-providers may not routinely produce detailed recording of the extent to which a need is managed. It may be necessary to ask the provider to complete a detailed 24/48 hour diary to demonstrate the nature and frequency of the needs and interventions, and their effectiveness.

> 11.2 Care should be taken when applying this principle. Sometimes needs may appear to be exacerbated because the individual is currently in an inappropriate environment rather than because they require a particular type or level of support – if they move to a different environment and their needs reduce this does not necessarily mean that the need is now 'well managed', the need may actually be reduced or no longer exist. For example, in an acute hospital setting, an individual might feel disoriented or have difficulty sleeping and consequently exhibit more challenging behaviour, but as soon as they are in a care home environment, or their own home, their behaviour may improve 2 without requiring any particular support around these issues.
>
> 11.3 The fact that an individual has a well-managed need does not, of itself, mean that they are either eligible or not eligible for NHS continuing healthcare. However, well-managed needs should be considered as part of the eligibility decision-making process. For more information see DST user notes paragraph 27.

4.38 This suggests that, somewhat paradoxically, the patient's reduced level of need in a particular domain arising from good management care should largely be ignored unless the intervention has "*has permanently reduced or removed an ongoing need*".

Scoring the levels of Need within the DST.

4.39 The level of need for any Care Domain can be assessed at:

- Low
- Moderate
- High
- Severe
- Priority [but only for the behaviour, breathing, drug-therapies or altered states of consciousness domains].

4.40 It will inevitably be the case that not all assessors agree on the appropriate domain for an individual. The DST does not provide for decisions to be taken on a majority basis but instead provides that where there is an agreement which cannot be

[24] Page 61 of the national Framework.

reconciled, the higher score by an assessor must be treated as the score of the panel. Paragraph 22 of the DST states:

> "If, after considering all the relevant evidence, it proves difficult to decide or agree on the level, the MDT should choose the higher of the levels under consideration and record the evidence in relation to both the decision and any significant differences of opinion. Please do not record an individual as having needs between levels. It is important that differences of opinion on the appropriate level are based on the evidence available and not on presuppositions about a person's need or generalised assumptions about the effects of a particular condition"

4.41 This part of the process is also described at PG33[25] which states as follows:

> **"PG 35What happens if MDT members cannot agree on the levels within the domains of the DST?**
>
> 35.1 The DST (paragraph 22) advises practitioners to move to the higher level of a domain where agreement cannot be reached but there should be clear reasoned evidence to support this. If practitioners find themselves in this situation they should review the evidence provided around that specific area of need and carefully examine the wording of the relevant DST levels to cross-match the information and see if this provides further clarity to move forwards or seek further evidence, although this should not prolong the 8 process unduly. If this does not resolve the situation, the disagreement about the level should be recorded on the DST along with the reasons for choosing each level and by which practitioner. This information should also be summarised within the recommendation so that the CCG can note this when verifying recommendations.
>
> 35.2 The practice of moving to the higher level where there is disagreement should not be used by practitioners to artificially steer individuals towards a decision that they have a primary health need where this is not justified. It is important that this is monitored during the CCG audits of recommendations and processes so that individual practitioners found to be using the 'higher level' practice incorrectly can be identified. Discussion may need to take place with these practitioners and possibly further training offered.

[25] See page 77/8 of the National Framework.

35.3 If practitioners are unable to reach agreement, the higher level should be accepted and a note outlining the position included within the recommendation on eligibility. As part of CCGs' governance responsibilities, they should monitor occurrences of this issue. Where regular patterns are identified involving individual teams or practitioners this should be discussed with them and where necessary their organisations to address any practice issues"

4.42 Thus, in effect, the final score involves levelling up to the score of the member of the MDT who gives the domain the highest score. In contrast, the patient or members of the patient's family are entitled to be present at the meeting but their views on the severity of a domain are no decisive. PG36 explains:

"PG 36 What happens if the individual concerned or their representative disagrees with any domain level when the DST is completed?

36.1 Whilst the individual and/or their representative should be fully involved in the process and be given every opportunity to contribute to the MDT discussion, the formal membership of the MDT consists of the practitioners involved. The approach described in PG35 above applies to disagreements between practitioners and not when an individual or their representative disagrees with individual domain levels chosen in the completion of the DST. However, concerns expressed by individuals and representatives should be fully considered by reviewing the evidence provided. If areas of disagreement remain these should be recorded in the relevant parts of the DST"

4.43 The Decision Support Tool suggests that a patient is likely to be eligible for CHC if he or she has:

- A level of **priority** needs in any one of the four domains that carry this level.
- A total of two or more incidences of identified **severe** needs across all care domains.

4.44 The Guidance requires the MDT to complete the DST. However it also suggests that the panel provide a detailed report to assist the CCG panel which is charged with the final decision making process. This is set out at PG37[26] which provides:

"PG 37 What does the DST recommendation need to cover?

37.1 The recommendation should:

a) provide a summary of the individual's needs in the light of the identified domain levels and the information underlying these. This should include the individual's own view of their needs.

b) provide statements about the nature, intensity, complexity and unpredictability of the individual's needs, bearing in mind the explanation of these concepts provided in paragraphs 77 – 89 of the National Framework.

c) give an explanation of how the needs in any one domain may interrelate with another to create additional complexity, intensity or unpredictability.

d) in the light of the above, give a recommendation as to whether or not the individual
has a primary health need (with reference to paragraphs 77 – 89 of the National Framework). It should be remembered that, whilst the recommendation should make reference to all four concepts of nature, intensity, complexity and unpredictability, any one of these could on their own or in combination with others be sufficient to indicate a primary health need.

37.2 Although the core responsibility of MDTs is to make a recommendation on eligibility for NHS continuing healthcare, the recommendation could also indicate any particular factors to be considered when commissioning/securing the placement or care/support package required to meet the individual's needs (whether or not the individual has a primary health need).

37.3 Where the outcomes of the individual care domains do not obviously indicate a primary health need (e.g. a priority level in one domain or severe levels in two domains being found), but the MDT is using professional judgement to recommend

[26] See pages 78-79 of the National Framework.

that the individual does nonetheless have a primary health need, it is important to ensure that the rationale for this is clear in the recommendation.

37.4 Where an individual has a deteriorating condition, practitioners need to take this into account in reaching their conclusion on primary health need, considering the approaches set out in paragraph 38 of this Framework and being mindful of how that condition and the associated needs are going to progress before the next planned review. Where an individual has a deteriorating condition but eligibility for NHS continuing healthcare is not presently recommended, consideration should be given to setting an early review date. This should be clearly highlighted in the recommendation to the CCG who should ensure that the review is arranged at the appropriate time.

37.5 The recommendation for eligibility for NHS continuing healthcare should not be based upon an individual's specific condition or disease (e.g. stroke, cancer, Alzheimer's disease, dementia, etc.) but on the needs that are identified. Needs that give rise to eligibility can be from any condition or disease. Just because individuals with a particular condition or disease have previously been found to be eligible for NHS continuing healthcare does not mean that every individual with a similar condition or disease will be eligible. Each individual should be assessed in their own right and evidence provided around the range of their needs; the identification of a primary health need should not be prejudged without going through the proper process in each individual case.

37.6 All of the above information should be provided even if the recommendation is that the individual does not have a primary health need. The CCG is responsible for care planning and commissioning all services that are required to meet the needs of all individuals who qualify for NHS continuing healthcare, and for the healthcare part of a joint care package. However, it is beneficial if the MDT makes recommendations on the care package to be provided, based on the assessment and any care plan already developed, whether the CCG, LA or both will have responsibilities.

37.7 The written recommendation needs to provide as much detail as possible, but should be clear and concise, to enable the CCG and the individual to understand the rationale behind the recommendation.

37.8 As the individual or their nominated representative should receive a copy of the DST it is important that it is legible, and free from jargon and abbreviations.

37.9 A copy of the completed assessment, DST and other documents should be forwarded to the CCG"

4.45 The test for the decision maker under the 2012 Regulations is solely whether the patient has a "Primary Healthcare Need". The multi-disciplinary team is usually expected to recommend that the patient has a "Primary Health Need" if the patient has a priority need in one domain or two or more instances of severe needs. However the Decision Support Tool only provides indicators to assist in the "Primary Healthcare Need" decision, but does not mandate an outcome.

4.46 The decision maker is fully entitled to conclude that, given the individual clinical circumstances, the patient does not have a Primary Health Need despite having a priority level of needs in one of the four domains that carry this level or two or more identified severe needs. The ultimate decision is a matter for the clinical judgment of the decision maker (usually a CHC panel acting as a decision maker on behalf of the CCG). The panel should be informed by the outcome of the DST as reported by the multi-disciplinary team, but must reach its own decision on the tests set out in the 2012 Regulations. The Guidance states that the assessment should not be carried out in a mechanistic way and, depending on the clinical facts, the team is entitled to recommend that the patient has a Primary Health Need if there is:

- one domain recorded as severe, together with needs in a number of other domains, or
- a number of domains with high and/or moderate needs,

4.47 In these cases, the team needs to look at overall level and severity of medical needs, the interactions between needs in different care domains, and the evidence from risk assessments. All these should be taken into account in deciding whether to make a recommendation of eligibility for NHS Continuing Healthcare. The Guidance however notes that it is <u>not</u> possible to equate a number of incidences of one level with a number of incidences of another level. The team should not, for example conclude that 'two moderates equals one high'.

4.48 Ultimately, the recommendation must be one of professional judgment by the multi-disciplinary team. It is therefore inevitable that there will be some variations between the assessments conducted by different professionals. A single set of national criteria and a single Decision Support Tool assist in improving consistency between decisions within a CCG and between different CCGs but some degree of inconsistency is inevitable given the professional judgments that need to made within the multi-disciplinary team. Provided the assessments are carried out conscientiously, it is more important to carry out accurate assessments on the clinical information available than to be over concerned about consistency between this case and another which, however similar, cannot ever be identical.

Consultation with Social Services.

4.49 Regulation 22(1) of the 2102 Regulations provides that CCGs must, as far as reasonably practicable, consult with Social Services before making a final decision about whether a patient qualifies for CHC. There is a duty on Social Services Departments to provide advice and assistance to CCGs when they are consulted. If the local authority has any paperwork concerning the patient including any assessment that a local authority has conducted to determine if the patient is in need of community care services, there is a duty on the local authority to disclose this to assist the CCG. The consultation stage should happen after the completion of the assessment using the Decision Support Tool but before the eligibility decision is made.

4.50 PG 76[27] explains the role of local authorities as follows:

> "PG 76 What is the role of the LA in NHS continuing healthcare?
> 76.1 The Standing Rules require CCGs to consult, so far as is reasonably practicable, with the relevant social services authority before making a decision on a person's

[27] See page 100 of the National Framework.

eligibility for NHS continuing healthcare. (The Ordinary Residence Guidance 2011[41] should be used to identify the relevant social services authority.)
76.2 Social services authorities shall provide advice and assistance to a CCG over individual cases as far as reasonably practicable. This duty applies regardless of whether a community care assessment is needed and is separate from the LA's duty to carry out assessments under section 47 of the NHS and Community Care Act 1990.

76.3 However, once such a case has been brought to the attention of the social services authority, in addition to giving advice and assistance it should, having regard to the facts of the case, also consider whether a community care assessment is required. Where community care assessments have been carried out, the LA should use information from these assessments to assist the CCG in carrying out its responsibilities.

76.4 The roles that a LA should undertake as part of this duty include:

- making staff available wherever practicable to be part of multidisciplinary teams (MDTs) which will undertake joint assessments and jointly complete the DST (including where the individual is a self-funder)

- contributing to eligibility panels (where these exist) and participating in the decision-making process on eligibility

- making staff available to undertake joint reviews

- having systems for responding promptly to requests for information when the CCG has received a referral for NHS continuing healthcare

- working jointly with the CCG in the planning and commissioning of care/ support for individuals deemed eligible for NHS continuing healthcare wherever appropriate, sharing expertise and local knowledge (whilst recognising that CCGs retain formal commissioning and care planning responsibility for those eligible for NHS continuing healthcare).

76.5 LAs shall make nominations to the Board of potential members of Independent Review Panels (IRPs) whenever requested by the Board and, where appointed, to make their nominees available to participate in IRPs as far as reasonably practicable"

4.51 The CCG should provide as much information to the local authority about the case as the local authority reasonably requires. Provided assurances are given by both sides about maintaining professional confidentiality (which should not be a problem with professional social workers), the Data Protection Act 1998 should not prevent the flow of relevant clinical information between the local authority. The CCG can rely on the statutory duty to consult under Regulation 22 of the 2012 Regulations to justify the disclosure of sensitive personal data about the patient to the local authority. It thus appears that, unless there are very special circumstances, the local authority are entitled to see all the case papers concerning the patient to assist them to respond to the application for CHC.

4.52 However, the local authority do not have an automatic right to see the information for other purposes, such as following up any concerns they may have about other service users. CCG staff should seek advice if they are concerned that there is a request from the local authority or anyone else (including the police) to use the information collected in the CHC process for any purpose other than assessing if a patient is entitled to CHC.

4.53 The role of local authority at this stage is to have the chance to comment on the assessment and its recommendations, and to feed their views into the decision making process. But the local authority does not hold a veto. The CCG is the sole decision maker on CHC eligibility as the Court of Appeal confirmed in *St Helens Borough Council v Manchester Primary Care Trust & Anor*[28] [2008] EWCA Civ 931 (06 August 2008).

4.54 The CCG must take any views expressed by local authority colleagues into account when taking the CHC eligibility decision. Tensions between the CCG and the local authority can mean that the CCG ends up disagreeing with the local authority's views on the right outcome of an individual case. The local authority may consider that a

patient is eligible for CHC and thus seek to press the CCG to fund a patient's on-going care (supported by the patient and/or the family). However, it is not unknown for the CCG to disagree with views strongly expressed by local authority colleagues. Any such disagreement should not prevent the CCG making a decision because the duty on the CCG under the Regulations is to consult the local authority, which does not require consensus decision making. The local authority holds no veto and the decision making process should not be set up so as to give the local authority a veto. Disputes between CCGs and local authorities are considered below.

4.55 If the local authority fail to respond to a request to provide input into the CHC process relating to a particular patient, the CCG are entitled to press ahead to the decision making phase without the local authority input.

Who within the CCG makes the eligibility decision?

4.56 The eligibility decision can be made by a person or committee authorised under the CCG's Standing Orders to take the decision on behalf of the CCG. This will usually be a nominated officer or a panel which is constituted to review the assessments and reach a decision. There is considerable flexibility in the Department of Health Model Standing Orders for CCGs to permit CCGs to delegate decision making by a CCG to a committee which includes individuals who are not employed by the CCG. Thus, the CCG panel could include colleagues from Social Services or patient user groups, provided that the body is constituted as a committee of the CCG.

4.57 The membership, terms of reference and decision making powers of the Panel should be approved by the CCG Governing Body. Many CCGs have colleagues from Social Services on the panel which makes the final decisions on eligibility, but it is not appropriate to set up the decision making process of the committee in such a way that those from outside the CCG have a right of veto or constitute a majority for an

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[2828] http://www.bailii.org/ew/cases/EWCA/Civ/2008/931.html [should just be fn 8 not 88]

vote on the issue of eligibility. The CCG should not leave itself in a position where CCG staff are unable to take a decision that a patient is or is not eligible for CHC.

What weight should be given to the MDT's assessment as set out in the DST?

4.58 Regulation 21(5)(b) of the 2012 Regulations provides that the purpose of the DST is to "*inform*" the decision of the CCG as to whether the patient has a "primary health need". The wording of the Regulation thus suggests that the panel is required to take the DST into account in reaching a decision but is not bound to adopt the same conclusions as the MDT which complied the DST. However the National Framework suggests that the DST should do more than "inform" the decision of the panel, in that it suggests that the panel should only depart from the recommendation of the MDT as set out in the DST in exceptional cases. This approach is explained at paragraphs 91 to 93 of the National Frame work which provide:

> "91. The CCG may choose to use a panel to ensure consistency and quality of decision-making. However, a panel should not fulfil a gate-keeping function, and nor should it be used as a financial monitor. Only in exceptional circumstances, and for clearly articulated reasons, should the multidisciplinary team's recommendation not be followed. A decision not to accept the recommendation should never be made by one person acting unilaterally"
>
> 92. The CCG may ask a multidisciplinary team to carry out further work on a Decision Support Tool if it is not completed fully or if there is a significant lack of consistency between the evidence recorded in the Decision Support Tool and the recommendation made. However, the CCG should not refer a case back, or decide not to accept a recommendation, simply because the multidisciplinary team has made a recommendation that differs from the one that those who are involved in making the final decision would have made, based on the same evidence.
>
> 93. CCGs should not make decisions in the absence of recommendations on eligibility from the multidisciplinary team, except where exceptional circumstances require an urgent decision to be made. The final eligibility decision should be independent of budgetary constraints, and finance officers should not be part of a decision-making panel"

4.59 The suggestion that the panel should only depart from the conclusions of the MDT in exceptional circumstances is reinforced in PG40[29] which provides:

"PG 40 What should the role of the CCG decision-making process be?

40.1 The role of the CCG decision-making processes, whether by use of a panel or other processes should include:

- verifying and confirming recommendations on eligibility made by the MDT, having regard to the issues in PG41 below;
- agreeing required actions where issues or concerns arise.

40.2 CCG decision-making processes should not have the function of:

- financial gatekeeping
- completing/altering DSTs
- overturning recommendations (although they can refer cases back to an MDT for further work in certain circumstances – see below)"

4.60 Practice Guidance 41[30] also provides more details about the "exceptional circumstances" in which a panel is said to be entitled to depart from a recommendation from the MDT. It provides:

PG 41 What are the 'exceptional circumstances' under which a CCG or panel might not accept an MDT recommendation regarding eligibility for NHS continuing healthcare?

41.1 Eligibility recommendations must be led by the practitioners who have met and assessed the individual. Exceptional circumstances where these recommendations may not be accepted by a CCG include:

[29] See pages 82/3 of the National Framework.
[30] See page 82.

- where the DST is not completed fully (including where there is no recommendation)
- where there are significant gaps in evidence to support the recommendation
- where there is a obvious mismatch between evidence provided and the recommendation made
- where the recommendation would result in either authority acting unlawfully.

41.2 In such cases the matter should be sent back to the MDT with a full explanation of the relevant matters to be addressed. Where there is an urgent need for care/support to be provided, the CCG (and LA where relevant) should make appropriate interim arrangements without delay. Ultimately responsibility for the eligibility decision rests with the CCG"

4.61 However, this part of the Guidance is open to the objection that, if the statutory scheme in the 2012 Regulations had wanted decision making panels to be bound by the conclusions of the MDT as expressed in the DST in all but exceptional circumstances, it could have said so but it did not. In contrast regulation 23(8) of the 2012 Regulations provides that a CCG is required to implement the decision of the NHS England review panel "*unless it determines …. that there are exceptional reasons not to do so*". It is therefore probably an unacceptable gloss on the statutory decision making scheme for the decision making panel to be required to find "exceptional circumstances" before it is entitled to reach a different decision from the MDT as expressed in the DST. The better view is that the panel has a duty to make its own decision as to whether the patient has a primary health need, duly informed by the views of the MDT as expressed in the DST, and that in doing so it should place considerable weight on the views of the DST. However, notwithstanding the duty to give considerable weight to the contents of the DST, the panel has to reach its own conclusions and is not limited to following the DST where is can articulate exceptional circumstances.

How should the CCG decision making panel make its decision?

4.62 Regulation 21(5)(b) provides that the first question the decision making panel has to decide is whether the patient has a primary health need. Regulation 21(6) then provides:

> "If a relevant body decides that a person has a primary health need in accordance with paragraph (5)(b), it must also decide that that person is eligible for NHS Continuing Healthcare"

4.63 The CCG's judgment as to whether a person has a primary health need will be reached in part by looking at the medical support the patient requires on a day to day basis to meet their needs using the assessment produced by the Decision Support Tool. Paragraph 35 of the National Framework states that a primary healthcare need is assessed according to the following aspects of a patient's needs:

- **Nature**: the type of needs, and the overall effect of those needs on the individual, including the type ("quality") of interventions required to manage them;
- **Intensity**: both the extent ("quantity") and severity (degree) of the needs, including the need for sustained care ("continuity");
- **Complexity**: how the needs arise and interact to increase the skill needed to monitor and manage the care;
- **Unpredictability**: the degree to which needs fluctuate, creating difficulty in managing needs; and the level of risk to the person's health if adequate and timely care is not provided.

4.64 Paragraph 36 of the National Framework goes on to state that:

> "Each of these characteristics may, in combination or alone, demonstrate a primary health need, because of the quality and/or quantity of care required to meet the individual's needs"

4.65 Paragraphs 3.5 and 3.6 of the Practice Guidance[31] additionally state:

> "3.5 Whilst there is not a legal definition, in simple terms an individual has a primary health need if, having taken account of all their needs (following completion of the DST), it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs.
>
> 3.6 Primary health need is not about the reason why someone requires care or support, nor is it based on their diagnosis; it is about their overall actual day-to-day care needs taken in their totality. Indeed it could be argued that most adults who require a package of health and social care support do so for a health-related reason (e.g. because they have had an accident or have an illness or disability). It is the level and type of needs themselves that have to be considered when determining eligibility for NHS continuing healthcare"

4.66 At paragraph 3.8 the Practice Guidance then gives the following advice about how to approach the four characteristics of nature, intensity, complexity and unpredictability of a patient's needs:

> "3.8 Four characteristics of need, namely 'nature', 'intensity', 'complexity' and 'unpredictability' 'may help determine whether the 'quality' or 'quantity' of care required is beyond the limit of an LA's responsibilities, as outlined in the Coughlan case (a summary of the case can be found at Annex B). It is important to remember that each of these characteristics may, alone or in combination, demonstrate a primary health need, because of the quality and/or quantity of care that is required to meet the individual's needs.
>
> 3.9 It may be helpful for MDTs to think about these characteristics in terms of the sorts of questions that each generates. By the MDT answering these questions they can develop a good understanding of the characteristic in question. The following questions are not an exhaustive list and are not intended to be applied prescriptively.
>
> **'Nature'** is about the characteristics of both the individual's needs and the interventions required to meet those needs.
>
> Questions that may help to consider this include:

[31] See page 51 of the National Framework

- How does the individual or the practitioner describe the needs (rather than the medical condition leading to them)? What adjectives do they use?
- What is the impact of the need on overall health and well-being?
- What types of interventions are required to meet the need?
- Is there particular knowledge/skill/training required to anticipate and address the need? Could anyone do it without specific training?
- Is the individual's condition deteriorating/improving?
- What would happen if these needs were not met in a timely way?

'Intensity' is about the quantity, severity and continuity of needs.

Questions that may help to consider this include:

- How severe is this need?
- How often is each intervention required?
- For how long is each intervention required?
- How many carers/care workers are required at any one time to meet the needs?
- Does the care relate to needs over several domains?

'Complexity' is about the level of skill/knowledge required to address an individual need or the range of needs and the interface between two or more needs.

Questions that may help to consider this include:

- How difficult is it to manage the need(s)?
- How problematic is it to alleviate the needs and symptoms?
- Are the needs interrelated?
- Do they impact on each other to make the needs even more difficult to address?
- How much knowledge is required to address the need(s)?
- How much skill is required to address the need(s)?
- How does the individual's response to their condition make it more difficult to provide appropriate support?

'Unpredictability' is about the degree to which needs fluctuate and thereby create challenges in managing them.

Questions that may help to consider this include:

- Is the individual or those who support him/her able to anticipate when the need(s) might arise?
- Does the level of need often change? Does the level of support often have to change at short notice?
- Is the condition unstable?
- What happens if the need isn't addressed when it arises? How significant are the consequences?
- To what extent is professional knowledge/skill required to respond spontaneously and appropriately?
- What level of monitoring/review is required?"

4.67 Panels should bear in mind that all sick and vulnerable adults require a level of social support and, if they cannot be cared for in their own homes or with relatives, have a need for suitable accommodation. Patients with complex medical conditions will inevitably need a measure of daily healthcare support as well. The panel must focus on what the patient needs at this time. For many patients, there is a possibility that their condition will change in the near future. The patient may improve or his or her medical condition may deteriorate. If this happens then eligibility for CHC should be reconsidered when the changed facts are known. However, the panel needs to make a decision on the patient's clinical condition as it is at that date. A patient should not become eligible for CHC because they have a medical condition which, if not managed properly, may be life threatening or require intensive medical intervention unless there is an intense intervention at present to avoid a deterioration. The panel should focus on the nature, intensity, complexity and unpredictability of the patient's condition at that point to determine eligibility for CHC.

4.68 There are particularly difficult issues where a patient has a deteriorating medical condition (but where the Fast Track Pathway Tool conditions are not met). Paragraph 38 of the National Framework provides as follows:

> "It is also important that deterioration is taken into account when considering eligibility, including circumstances where deterioration might reasonably be regarded as likely in the near future. This can be reflected in several ways:

- Where it is considered that deterioration can reasonably be anticipated to occur before the next planned review, this should be documented and taken into account. This could result in immediate eligibility for NHS continuing healthcare (i.e. before the deterioration has actually occurred). The anticipated deterioration could be indicative of complex or unpredictable needs.

- Where eligibility is not established at the present time, the likely deterioration could be reflected in a recommendation for an early review, in order to establish whether the individual then satisfies the eligibility criteria.

- If an individual has a rapidly deteriorating condition that may be entering a terminal phase, they may need NHS continuing healthcare funding to enable their needs to be met urgently (e.g. to allow them to go home to die or appropriate end of life support to be put in place). This would be a primary health need because of the rate of deterioration. In all cases where an individual has such needs, consideration should be given to use of the Fast Track Pathway Tool, as set out in paragraphs 97 – 107.

- Even when an individual does not satisfy the criteria for use of the Fast Track Pathway Tool, one or more of the characteristics listed in paragraph 35 may well apply to those people approaching the end of their lives, and eligibility should always be considered"

4.69 A balance of medical and non-medical needs need is probably not sufficient to lead to a conclusion that the patient has a primary health need. The issue for the CCG is whether the above factors suggest that the patient's main or predominant need is for healthcare support, with a subsidiary need for accommodation and social care, or whether the patient has a main or predominant need for accommodation and social care, albeit that the patient also has a variety of healthcare needs. There will be cases where a patient with a complex medical condition is properly managed by staff who know the patient very well. This may lead to a situation where a previously unpredictable medical condition is now much less uncertain. It may mean that the intensity and severity of the patient's needs is less than it was a few months previously. Panels need to give proper recognition to carers who are able to bring

about such benefits and should not underestimate the complexity of the patient's condition because it is managed predominantly by non-specialist staff. However it should give due weight to such improvements and may well conclude that, as a result, the patient no longer qualifies for CHC. The issue should always come back to the single issue as to whether the patient has a primary health need.

4.70 The setting in which the patient is provided with care is not usually relevant to a decision about CHC entitlement. CHC can be provided to patients in their own home or in a care home.

The alternative ground: Needs beyond what a Local Authority can be expected to provide.

4.71 Regulation 21(7) of the 2012 Regulations picks up the tests outlined in *Coughlan*[32] and requires the CCG to apply them as an alternative route for the panel to reach the conclusion that the patient has a primary medical need. It provides:

> "In deciding whether a person has a primary health need in accordance with paragraph (5)(b), a relevant body must consider whether the nursing or other health services required by that person are—
>
> (a) where that person is, or is to be, accommodated in relevant premises, more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for a person's means, under a duty to provide; or
>
> (b) of a nature beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide,
>
> and, if it decides that the nursing or other health services required do, when considered in their totality, fall within sub-paragraph (a) or (b), it must decide that that person has a primary health need"

4.72 It follows that, in reaching the decision as to whether a patient has a primary health need, the CCG panel is required to look at the "*nursing or other health services*

required by that person" and then ask itself 2 questions. First, the CCG must ask itself if the person is in a care home or is required to be placed in a care home. If so, the CCG needs to ask itself whether the individual's needs are:

> "more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for a person's means, under a duty to provide"

4.73 If the patient does have a need for "*nursing or other health services"* which is more than is appropriate to be provided within social care accommodation (i.e. accommodation funded by the local authority under the Care Act 2014), the CCG is required to reach the conclusion that the patient has a primary health need and hence is eligible for CHC.

4.74 The second part of Regulation 21(7) applies where the patient is not in a care home, which will usually mean that the person is living in their own home or with relatives. This part of the test looks at the nature of the package of domiciliary services that are required by a patient who is living outside of a care. In such a case the CCG is required to consider the "*nursing or other health services required by that person*" and ask whether these needs are of a nature beyond which a social services authority could be expected to provide. If the services are beyond those which a social services authority could be expected to provide, the CCG panel must find that the patient is eligible for CHC.

4.75 It is good practice to have these questions set out on the form that those undertaking the assessment have to complete to ensure that the CCG addresses its mind to them as part of the assessment process. The thinking in this part of the Regulation (which is identical to the Directions which preceded the Regulations), emerges from the observations of the Court of Appeal in *Coughlan)*[33]*.* The wording means that if the CCG decides that, looking at the patient's needs as a whole, it is

[32] See paragraphs 2.11ff above.
[33] See paragraphs 2.11 above.

inappropriate to look to social services to provide day to day care for the person, the CCG is required to conclude that the patient qualifies for CHC.

4.76 These provisions exist to ensure that patients are not left in circumstances where their needs are not serious enough to satisfy for CHC but their nursing or other health service needs are too medically complex to be provided by a local authority. However CCG panels need to bear a number of points in mind when addressing this issue:

- There are a wide range of health functions which local authorities are required to provide under a variety of statutes. The range and quality of health and health related services that local authorities can provide appears to be far greater than some local authorities assume;

- The test asks the CCG to focus on what the CCG considers it is reasonable to ask the local Social Services to provide. That may well be a higher or lower level of services than the local authority social services are in fact prepared to provide. The range of service users supported by the social services department of a local authority may be more generous in their provision of services than the CCG considers is reasonable. In that case, a patient may qualify for CHC even if the local social services could have provided support for the patient. Equally, however local authority social services cannot cut back on social care provision and thereby seek to shift patients from social to health care by simply failing to provide classes of services. If the CCG considers that a patient's needs could properly be met by the local authority (even if the local authority social services may refuse to provide such services), it may be entirely appropriate for the CCG to decline to provide CHC support for the patient.

- The NHS does not walk away from a patient if the patient is not eligible for CHC. CCGs provide a wide range of medical support services to a patient in a nursing

home or in the community who do not qualify for CHC, including NHS funded nursing care.

4.77 Once the decision has been made, it needs to be communicated to everyone who has a legitimate interest in knowing the decision. PG 42[34] provides:

"P**G 42How should decisions be communicated to the individual/ representative?**

42.1 Once the recommendation is confirmed by the CCG, the individual should be informed in writing in an appropriate language or format as soon as possible (although this could be preceded by verbal confirmation where appropriate), including the reasons for the decision and details of who to contact if they wish to seek further clarification or request a review of the decision. In most circumstances a fully completed DST with a covering letter confirming the decision and giving the above details will be sufficient for this purpose. Confirmation of the care package to be provided could be included within the letter or, if not known at that stage, should be supplied as soon as available"

5 The Fast Track Pathway decision making processes.

5.1 The CHC processes recognise that there will be patients whose needs are so urgent that a decision needs to be taken more urgently than permitted by the usual processes. The Fast Track Pathway Tool is available for such cases. The statutory framework for this is set out in Regulations 21(8) to (10) of the 2012 Regulations which provide:

"(8) Paragraphs (2) to (6) do not apply where an appropriate clinician decides that—

a) an individual has a primary health need arising from a rapidly deteriorating condition; and

b) the condition may be entering a terminal phase,

[34] See page 83 of the National Framework

and that clinician has completed a Fast Track Pathway Tool stating reasons for the decision.

(9) A relevant body must, upon receipt of a Fast Track Pathway tool completed in accordance with paragraph (8), decide that a person is eligible for NHS Continuing Healthcare.

(10) Where an assessment of eligibility for NHS Continuing Healthcare has been carried out, or a relevant body has received a Fast Track Pathway Tool completed in accordance with paragraph (8), the relevant body must—

(a) notify the person assessed (or someone lawfully acting on that person's behalf), in writing, of the decision made about their eligibility for NHS Continuing Healthcare, the reasons for that decision and, where applicable, the matters referred to in paragraph (11); and

(b) make a record of that decision"

5.2 It follows that the key differences between the Fast Track and the normal track are:

a) The Fast Track is only appropriate where a patient has a "rapidly deteriorating condition" which may be entering a "terminal phase";

b) The decision maker as to whether these conditions are met is an "appropriate clinician" and not the CCG; and

c) Once the decision is made by an appropriate clinician that the statutory test is met, the CCG has a statutory duty to make the decision that the patient is eligible for CHC. The appropriate clinician is thus a delegated decision maker on behalf of the CCG: see by analogy *R (Crudace) v Northumbria Police Authority* [2012] EWHC 112 (Admin) at paragraphs 63 to 70.

5.3 The term "appropriate clinician" is defined in Regulation 21(13) as follows:

""appropriate clinician" means a person who is—

(a) responsible for the diagnosis, treatment or care of the person under the 2006 Act in respect of whom a Fast Track Pathway Tool is being completed, and

(b) a registered nurse or a registered medical practitioner"

5.4 The "Fast Track Pathway Tool" is published by the Department of Health[35]. The purpose of the Fast Track Pathway Tool is explained at paragraph 13 as follows:

"The purpose of the Fast Track Pathway Tool is to ensure that individuals with a rapidly deteriorating condition, which may be entering a terminal phase, are supported in their preferred place of care as quickly as possible. It means that a CCG takes responsibility for commissioning and funding appropriate care. Once this has happened, a CCG, and its partners can proceed, where appropriate, with reaching a decision on longer-term NHS continuing healthcare eligibility. No one who has been identified through the fast-track process as being eligible for NHS continuing healthcare should have this funding or support removed without their eligibility being reviewed in accordance with the review processes set out in the National Framework. The review should include completion of the Decision Support Tool (DST) by a multidisciplinary team, including a recommendation on eligibility. This overall process, including how personal information will be shared between different organisations and healthcare professionals involved in delivering care, should be carefully and sensitively explained to the individual and, where appropriate, their family. Careful decision making is essential to avoid the undue distress that might result from a person moving in and out of NHS continuing healthcare eligibility within a very short period of time. Where an individual receiving services through use of the Fast Track Pathway Tool is expected to die in the very near future, CCGs should continue to take responsibility for the care package until the end of life"

5.5 This approach is replicated at paragraphs 97 to 107 of the National Framework which provide:

Fast Track Tool

97. Individuals with a rapidly deteriorating condition that may be entering a terminal phase, may require 'fast tracking' for immediate provision of NHS continuing

healthcare. The Fast Track Tool should be completed by an appropriate clinician, who should give the reasons why the person meets the criterion required for the fast-tracking decision. 'Appropriate clinicians' are those persons who are, pursuant to the 2006 Act, responsible for an individual's diagnosis, treatment or care and who are medical practitioners (such as consultants, registrars or GPs) or registered nurses. The clinician should have an appropriate level of knowledge or experience of the type of health needs, so that they are able to comment reasonably on whether the individual has a rapidly deteriorating condition that may be entering a terminal phase.

98. Appropriate clinicians can include clinicians employed in voluntary and independent sector organisations that have a specialist role in end of life needs (for example, hospices), provided they are offering services pursuant to the 2006 Act. Others involved in supporting those with end of life needs, including those in wider voluntary and independent sector organisations, may identify the fact that the individual has needs for which use of the Fast Track Tool would be appropriate. They should contact the appropriate clinician who is responsible for the diagnosis, care or treatment of the individual and ask for consideration to be given to completion of the Fast Track Tool.

99. The completed Fast Track Tool should be supported by a prognosis, if available. However, strict time limits that base eligibility on some specified expected length of life remaining should not be imposed: it is the responsibility of the appropriate clinician to make a decision based on the needs of the person.

100. Where a recommendation is made for an urgent package of care via the fast-track process, this should be accepted and actioned immediately by the CCG. It is not appropriate for individuals to experience delay in the delivery of their care package while concerns over the use of the Fast Track Tool are resolved. CCGs should carefully monitor use of the tool and raise any specific concerns with clinicians, teams and organisations. Such concerns should be treated as a separate matter from the task of arranging for service provision in the individual case.

101. No one who has been identified through the fast-track process as eligible for NHS continuing healthcare should have this funding removed without the eligibility being reviewed in accordance with the review processes set out in paragraphs 139 - 144 . The review should include completion of a Decision Support Tool by a multidisciplinary team, including them making a recommendation on eligibility.

[35] See https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

102. The purpose of the Fast Track Tool is to ensure that individuals with a rapidly deteriorating condition that may be entering a terminal phase are supported in their preferred place of care as quickly as possible. This overall process including how personal information will be shared between different organisations and healthcare professionals involved in delivering care, should be carefully and sensitively explained to the individual and (where appropriate) their representative. Careful and sensitive decision-making is essential in order to avoid the undue distress that might result from a person moving in and out of NHS continuing healthcare eligibility within a very short period of time.

103. Where an individual who is receiving services from use of the Fast Track Tool is expected to die in the very near future, the CCG should continue to take responsibility for the care package until the end of life.

104. It is important to bear in mind that this is not the only way that someone can qualify for NHS continuing healthcare towards the end of their life. The Decision Support Tool asks practitioners to document deterioration (including observed and likely deterioration) in a person's condition, so that they can take this into account in determining eligibility using the Decision Support Tool. However, this should not be used as a means of circumventing use of the Fast Track Tool when individuals satisfy the criteria for its use.

105. Where deterioration can be reasonably anticipated to take place in the near future, this should also be taken into account, in order to avoid the need for unnecessary or repeat assessments.

106. In end of life cases, CCGs and LAs should take particular account of paragraphs 169 - 171 regarding person-centred commissioning and procurement arrangements.
107. NHS continuing healthcare assessments, care planning and commissioning for those with end of life needs should be carried out in an integrated manner, as part of the individual's overall end of life care pathway, and should reflect the approaches set out in the national End of Life Care Strategy19, with full account being taken of patient preferences, including those set out in advance care plans"

5.6 Further Guidance on the use of the Fast Track Tool is provided in the Practice Guidance sections at pages 83 to 84 of the National Framework.

5.7 Care planning for those in a terminal phase may need to be completed quickly once an eligibility decision is made. PG52 recommends care planning should be completed within 48 hours if the Fast Track Tool is used. It provides:

> **"PG 52 How quickly could a hospital discharge take place following the completion of the Fast Track Tool?**
>
> 52.1 Standing Rules state that the CCG must, upon receipt of a completed Fast Track Pathway Tool, decide that the individual is eligible for NHS continuing healthcare. Action should be taken urgently to agree and implement the care package. CCGs should have processes in place to enable such care packages to be implemented quickly. Given the nature of the needs, this time period should preferably not exceed 48 hours from receipt of the completed Fast Track Pathway Tool. CCGs who receive significant numbers of Fast Track Pathway Tools could consider having staff dedicated to implementing fast-track care packages as this will avoid a conflict of time priorities with dealing with non-fast-track applications. Having dedicated staff could also facilitate close working with end of life care teams. CCGs should also consider wider arrangements that need to be in place to facilitate implementation of packages within 48 hours, such as protocols for the urgent provision of equipment. The CCG coordinator and the referrer should communicate effectively with each other to ensure well-coordinated discharge/support provision arrangements"

5.8 This Guidance thus suggests that CCGs are required to move very quickly to make suitable arrangements for a person in a terminal phase of life.

6 NHS Funded Nursing Care.

6.1 NHS Funded Nursing care is covered by Part 6 of the 2012 Regulations. Regulation 20 defines "nursing care" as follows:

> ""nursing care" means nursing care by a registered nurse and "nursing care by a registered nurse" has the same meaning as in section 49(2) of the Health and Social Care Act 2001"

6.2 The definition of "nursing care" in section 49 of the 2001 Act is:

"In this section "nursing care by a registered nurse" means any services provided by a registered nurse and involving–

(a) the provision of care, or

(b) the planning, supervision or delegation of the provision of care,

other than any services which, having regard to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse"

6.3 Regulation 28 defines the decision making process for determining if a patient is eligible for NHS funded nursing care as follows:

"28.—(1) Subject to paragraphs (2) and (3), where it appears to a relevant body in respect of a person for whom it has responsibility that that person—

a) is resident in relevant premises or may need to become resident in such premises; and

b) may be in need of nursing care,

that body must carry out an assessment of the need for nursing care.

(2) Before carrying out an assessment under paragraph (1), the relevant body must consider whether its duty under regulation 21(2) is engaged, and if so, it must comply with the requirements of regulation 21 prior to carrying out any assessment under this regulation.

(3) Paragraph (1) does not apply if a relevant body has made arrangements for providing the person with NHS Continuing Healthcare.

(4) Where—

(a) the relevant body has carried out an assessment pursuant to regulation 21(2); but

(b) paragraph (3) does not apply because a decision has been made that the person is not eligible for NHS Continuing Healthcare,

that body must nevertheless use that assessment, wherever reasonably practicable, in making its assessment under paragraph (1).

(5) Where—

(a) the relevant body determines that a person has a need for nursing care pursuant to this regulation; and

(b) the person has agreed with that body that that person does want to be provided with such nursing care,

paragraph (6) applies.

(6) The relevant body must pay to a registered person for the relevant premises the flat rate in respect of that person's nursing care unless or until that person—

(a) has their need for nursing care assessed and it is determined that that person no longer has any need for nursing care;

(b) is no longer resident in the relevant premises;

(c) becomes eligible for NHS Continuing Healthcare pursuant to this Part; or

(d) dies"

6.4 This Regulation makes it clear that NHS funded nursing care is an NHS contribution towards the cost of care home fees for patient that are not eligible for fully funded CHC. Guidance on determining the need for NHS Funded nursing Care is provided at Annex D to the Guidance[36]. This provides:

Annex D: Determining the Need for NHS-funded Nursing Care

1. In all cases, individuals should be considered for eligibility for NHS continuing healthcare before a decision is reached about the need for NHS-funded nursing care (NHS-funded nursing care provided by registered nurses) in residential accommodation. In most cases, therefore, the individual will already have been considered for NHS continuing healthcare and will have had an associated

assessment, which should provide sufficient information to gauge the need for nursing care in residential accommodation. In certain circumstances, an individual who has been found not to be eligible for NHS continuing healthcare at the Checklist stage may still need an assessment of needs for NHS-funded nursing care. In such cases, an appropriate assessment should be completed. It may, therefore, be appropriate to use the Single Assessment Process (or similar), to ensure that all needs are identified and that the decisions reached are proportionate, reasoned and recorded.

2. Where the local authority (LA) also carries out an assessment of the individual's needs, it may be appropriate for the CCG to carry out an assessment for NHS-funded nursing care jointly with this process. Where an individual is funding his or her own care needs (apart from NHS-funded nursing care), CCGs should take particular care to ensure that there is clarity on the part of themselves, the relevant LA and the individual as to who is taking responsibility for the assessment, case management and review of the individual's needs on an ongoing basis.

3. The outcome of the above process should provide the CCG with sufficient information to establish an agreement with a care home for NHS-funded nursing services, and will trigger the CCG's responsibility to fund the care from a registered nurse through a single rate of payment.

4. Individuals who were in receipt of the high band of NHS-funded nursing care under the three-band system that was in force until 30 September 2007 are entitled to continue on the high band until:

> a) on review, it is determined that they no longer have any need for nursing care;
>
> b) on review, it is determined that their needs have changed, so that under the previous three-band system, they would have moved onto the medium or low bands.
> In this situation, the individual should be moved onto the single rate;
>
> c) they are no longer resident in a care home that provides nursing care;
>
> d) they become eligible for NHS continuing healthcare; or
>
> e) they die"

[36] See page 127 of the National Framework.

6.5 Patients cannot qualify both for CHC and NHS funded nursing care: see Regulation 28(3). Patients who have a need for nursing services but live at home do not qualify for the payment. This provision assumes that a patient living in their own home who needs nursing services will have those provided by district nurses or by a domiciliary care agency which is contracted by the relevant CCG to provide this service.

6.6 Regulation 28 imposes a duty on the CCG (or possibly NHS England) to carry out an assessment of the patient's need for nursing care. However, Regulation 28(4) provides that where a patient is found not to be eligible for CHC, the CHC assessment or the CHC Checklist should be used to determine the patient's eligibility for NHS funded nursing care.

6.7 The level of payment in November 2016 is £156.25 per week (supposedly on an "interim basis"). Before October 1 2007, there were three different levels or bands of payment for NHS-funded nursing care – low, medium and high. If a patient moved into a care home before October 1 2007, and was awarded the low or medium bands, the patient should have been transferred to the standard rate from that date. If the patient moved into a care home before October 1 2007 and was awarded the high band, NHS-funded nursing care continues to be paid at the higher rate. For 2015/16, the standard rate was fixed at £156.25. This represented a 40% increase on the previous rate. However the rate payable from 1 April 2017 was reduced to £155.05[37] and the higher rate was fixed at "£213.32. The standard rate is due to rise to £158.16 on 1 April 2018[38] and the higher rate will increase to £217.59.

6.8 Patients are entitled[39] to continue on the standard rate unless:

[37] See https://www.gov.uk/government/news/nhs-funded-nursing-care-rate-for-2017-to-2018
[38] See https://www.gov.uk/government/news/nhs-funded-nursing-care-rate-announced-for-2018-to-2019
[39] The entitlement is set out on the NHS Choice website at http://www.nhs.uk/chq/Pages/what-is-nhs-funded-nursing-care.aspx

a) The patient no longer has nursing needs;

b) The patient no longer lives in a care home that provides nursing;

c) The patient's nursing needs have reduced and, applying the previous tests, he or she is would no longer be eligible for the high band. In that case the patient will drop from the higher rate to the standard rate, or

d) The patient becomes entitled to CHC.

7 The legal relationship between NHS and local authority funded services.

7.1 Care for a service user which is delivered by a registered nurse cannot be delivered by the local authority. Local authorities also do not employ doctors, apart from for the discharge of their public health functions and care to an individual patient by a doctor will fall on the NHS, not on social care. However, all other highly specialised community care services that a local authority can provide to individuals who are accommodated outside an NHS hospital.

7.2 If a package of care services is needed to support someone who is disabled or ill, or to prevent them getting ill, and the care is of such a nature that it does <u>not</u> require a substantial and regular care input by a registered nurse or doctor, the primary duty to provide care for those with eligible needs lies on the local authority. There is, for example, a wide range of duties to the sick and disabled on local authorities under the Care Act 2014. In contrast, where a patient is eligible for CHC, a local authority will generally decide that the patient has no "need" for community care services because a package of accommodation, social and health care service should be funded by the NHS to meet all of the service user's eligible needs.

8 Reviews and appeals to NHS England by patients or relatives of eligibility decisions.

8.1 Regulation 21(11) of the 2012 Regulations provides for the patient to be informed of the CHC decision as follows:

> "(11) Where a relevant body has decided that a person is not eligible for NHS Continuing Healthcare, it must inform the person (or someone acting on that person's behalf) of the circumstances and manner in which that person may apply for a review of the decision if they are dissatisfied with—
>
> (a) the procedure followed by the relevant body in reaching that decision; or
>
> (b) the primary health need decision made in accordance with paragraph (5)(b)"

8.2 Unlike other provisions within the 2012 Regulations, Regulation 21(11) does not specifically require the CCG to give reasons for its decision. However paragraph 146 of the National Framework states:

> "the CCG should give clear reasons for its decision"

The duty to have regard to the National Framework thus probably means that the CCG has a legal duty to give coherent reasons for its eligibility decision.

8.3 Regulation 21(11) provides that the patient must be told that he or she can seek a review of the decision. Para 151 of the National Framework provides:

> "Each CCG should agree a local review process. These review processes should include timescales and should be made publicly available, and a copy should be sent to anybody who requests a review of a decision"

8.4 The CCG should devise and operate a procedure to enable staff who were not involved in the original decision to review decisions on CHC eligibility. This should be undertaken as quickly and thoroughly as is possible in the circumstances. This will rarely require the CCG to repeat in full the multi-disciplinary assessment. Nonetheless if there are areas of substantial concern identified in the review, this review may lead to the CCG re-running the assessment process. Once the review is

completed, the CCG should provide a response to the patient or their relatives explaining the decision that has been reached and the reasons for the decision.

8.5 If the patient or their relatives remain dissatisfied with the decision, they can both ask for a review and, if still dissatisfied, can appeal to a panel set up by NHS England. The options for the patient or their family are explained in PG 73 which provides:

> **"PG 73 What if the individual wishes to challenge the final eligibility decision made by the CCG?**
>
> 73.1 If the individual or their representative wishes to dispute the decision made and/or the process used to reach it, they can request an independent review through the Board as set out in this Framework. However, CCGs should always work with the individual and their representatives to seek to resolve the matter informally without the need for an IRP. Even when an IRP has been requested, CCGs should continue to seek to informally resolve the matter, up to the date of the IRP hearing itself. When the Board receives an IRP request they should contact the relevant CCG to establish what efforts have been made to achieve local resolution and the outcome. The Board can consider asking CCGs to attempt further local resolution prior to the IRP hearing. CCGs and the Board may receive requests that are outside the remit of the IRP process (i.e. that are not about the application of the eligibility criteria or the process followed to reach the decision). The eligibility criteria are set nationally by Standing Rules and so are not a matter for local review or complaints processes. If CCGs and the Board receive review requests about other non-IRP matters (for example, the nature of the care package to be provided) they should advise the individual to pursue the matter through the NHS complaints process. CCGs should consider publishing local processes and timescales for responding to complaints and concerns relating to NHS continuing healthcare on issues that fall outside of the IRP process"

8.6 The NHS England panel is under a duty to "review" the decision: see Regulation 23 of the 2012 Regulations. Regulations 23(8) and (9) provide that the CCG must follow the recommendation of the NHS England Review Panel unless it has exceptional reasons not to do so. Those "exceptional reasons" could be that the Review Panel has failed to apply the National Framework properly, has failed properly to understand the assessments that the CCG made of the patient's needs or has come to an irrational conclusion.

8.7 CCG staff should co-operate fully with the operation of such panels which will make final decisions on entitlement to CHC. If the NHS England appeal panel decides that the patient is eligible for CHC and that decision is accepted by the CCG, the CCG has a liability to meet the costs from the date of the decision. If the decision making process has taken more than 28 days, the CCG should reimburse the patient or family members for relevant care and accommodation costs involved from 28 days after the date when an application was made to the CCG for CHC support. If the CCG turns down the patient for CHC and this decision is reversed by the NHS England panel, an ex-gratia payment should be made to cover the costs incurred by whoever has funded the care whilst the decision making process was continuing: see paragraph 18 of Annex F to the National Framework.

8.8 A CCG is highly unlikely to have any legal responsibility to have a duty to meet care costs incurred before the date when an application was first made to the CCG for CHC support (although a claim can be made under the maladministration provisions which have been used for the extra-statutory CHC retrospective review processes).

Support for the patient whilst the review or appeal procedure is continuing

8.9 If the CCG makes the decision that a patient is not entitled to CHC, the CCG should nonetheless provide a package of appropriate health care for the patient but it entitled to refuse to enter into new agreements to fund accommodation or social care costs, even if the patient is challenging the CHC eligibility decision.

8.10 There can be considerable difficulties if the patient is waiting to be discharged from hospital and there is a dispute with either the relatives or social services about a package of services at home or about meeting care home fees whilst the review procedures are being carried through. There are a number of options that CCGs can consider in such circumstances:

a) It may be possible to agree with the local authority that the patient should go to a care home or have a package of domiciliary care at home to be funded by either the local authority or the CCG, and the paying party will be reimbursed by the CCG or local authority for the care home costs if the NHS England appeal is upheld; or

b) The same arrangement could be reached with the patient or with family members. Under such an arrangement the CCG could enter into a similar arrangement with the patient or relatives to meet the costs in short term, and for the CCG to be reimbursed if appeal is unsuccessful.

8.11 If agreement cannot be reached for any of the above options and this is preventing a patient being discharged from in-patient care, reference should be made to the relevant NICE Guidance on Transition between inpatient hospital settings and community or care home settings for adults with social care needs[40] to manage the process to ensure that a patient is moved out of hospital as soon as possible. However, the existence of a dispute with either the local authority or with the patient (or their relatives) is not a good reason for holding back from serving notices.

8.12 If the patient or their relatives makes it clear to Social Services that they do not wish to seek support from social services then the local authority generally have no duty to arrange accommodation for the patient. In those circumstances the usual route is for the either the CCG or the Acute Trust to seek legal advice about evicting the patient from the in-patient bed. A patient who remains in an NHS hospital bed after the time when the NHS Trust has decided that the patient has clinical needs to justify the bed is a trespasser. If necessary, an eviction order can be obtained from the county court: see *Barnet PCT v X* [2006] EWHC 787 (QB).

9 **Disputes between CCGs and local authorities over CHC eligibility.**

9.1 Unlike patients or their relatives, local authorities are unable to appeal to NHS England panels. Disputes between local authorities and CCGs need to be resolved using dispute resolution procedures agreed between the two public bodies. Regulation 22(2) of the 2102 Regulations provides:

> "(2) Where there is a dispute between a relevant body and the relevant social services authority about—
>
> (a) a decision as to eligibility for NHS Continuing Healthcare; or
>
> (b) where a person is not eligible for NHS Continuing Healthcare, the contribution of a relevant body or social services authority to a joint package of care for that person,
>
> the relevant body must, having regard to the National Framework, agree a dispute resolution procedure with the relevant social services authority, and resolve the disagreement in accordance with that procedure"

9.2 Thus there is a statutory duty on the CCG to have regard to the National Framework and they must "agree a dispute resolution procedure with the relevant social services authority". Once the dispute resolution procedure has been agreed, the CCG is under a statutory duty to use the procedure to resolve the disagreement.

9.3 This is confirmed at paragraph 159 of the National Framework which provides:

> "CCGs and LAs in each local area should agree a local disputes resolution process to resolve cases where there is a dispute between them about eligibility for NHS continuing healthcare, about the apportionment of funding in joint funded care/support packages, or about the operation of refunds guidance (see Annex F). Disputes should not delay the provision of the care package, and the protocol should make clear how funding will be provided pending resolution of the dispute. Where disputes relate to LAs and CCGs in different geographical areas, the disputes resolution process of the responsible CCG should normally be used in order to ensure resolution in a robust and National Framework for NHS Continuing Healthcare and

[40] See https://www.nice.org.uk/guidance/ng27/chapter/Recommendations

NHS-funded Nursing Care timely manner. This should include agreement on how funding will be provided during the dispute, and arrangements for reimbursement to the agencies involved once the dispute is resolved"

9.4 Annex F to the National contains Framework sets out the general statutory duties imposed on both NHS bodies and local authorities and urges them to comply with those duties until a CHC eligibility decision is made. It provides at paragraph 7:

"No individual should be left without appropriate support because statutory bodies are unable to agree on respective responsibilities"

9.5 Paragraph 19 of Annex F to the National Framework provides some more detail about dispute resolution procedures as follows:

"It is important that the Board/ CCGs and LAs have clear jointly agreed local processes for resolving any disputes that arise between them on the issues covered in this guidance. The Standing Rules Regulations and Directions to LAs require the Board or CCGs and LAs to have an agreed local process for resolving disputes between them on issues relating to eligibility for NHS continuing healthcare and for the NHS elements of joint packages. The Board, CCGs and LAs could extend the remit of their local disputes process to include disputes over refunds. Whatever disputes process is selected, it is important that it should not simply be a forum for further discussion but includes an identified mechanism for final resolution, such as referring the case to another CCG and LA and agreeing to accept their recommendation"

9.6 Further Guidance is provided at PG71 and PG72 which provides:

"96 PG 71 What factors need to be considered in local disputes processes?

71.1 It is important that local disputes processes include levels of escalation of the disputes, for example, by the matter initially being considered further by team managers from the CCG and LA and then increasing to senior management involvement as necessary. Disputes processes should also include a level by which the matter has to be finally resolved, even if it has not been resolved at lower levels. This could, for example, be by the matter being referred jointly to another to another CCG and LA, and agreeing to accept their recommendation. CCGs and LAs should carefully

monitor the use of their disputes process. Disputes should be reviewed after resolution for learning points and these should be fed back to those involved in the decision-making process in the case and also built into the training of MDT members as appropriate.

PG 72 What if the dispute crosses CCG/LA borders?

72.1 Where a dispute occurs between a CCG and LA in different areas (and therefore without a shared disputes resolution agreement) it is recommended that the local process applying to the CCG involved in the case is used. Where a dispute involves two CCGs, it is recommended to use the disputes process for the CCG area where the individual is residing at the outset of the relevant decision-making process. Thus if CCG A had made a placement in CCG B's area, it is CCG A's dispute process that should be used, even if the person is now physically residing in CCG B's area. Both CCGs should be able to play a full and equal role in the dispute resolution. Consideration could be given to identifying an independent person (who is not connected with either CCG) to oversee the resolution of the dispute. CCGs and LAs should consider agreeing and publishing local processes and timescales for responding to complaints and concerns relating to NHS continuing healthcare on issues that fall outside of the IRP process"

9.7 However well-meaning this may be, a statutory duty to "agree a procedure" or to operate an existing procedure which has been agreed with a different local authority is largely incapable of being enforced. Further, the reference to "*dispute resolution procedures*" being used to take decisions is somewhat problematic because the CCG is required by statute to remain as the ultimate decision maker throughout the process. Further there is no specific duty on the local authority to follow the procedures. The locally agreed procedures should provide, in effect, a further opportunity for the local authority to require the CCG to examine its own decision. They should cover:

a) Who in the local authority and CCG should review the dispute in the first instance;

b) An agreed timetable for that review;

c) A set of principles to guide the review which should include a recognition that it is not the role of the CCG to take decisions which are the statutory responsibility of the local authority and that it is not the role of the local authority to take decisions which are the statutory responsibility of the CCG, but that either body can ask the other to review their decisions;

d) An agreed process for the involvement of senior officers in the process;

e) An agreement that, in the event that the review procedures changes or modifies a decision, one public body will provide full reimbursement to the other in an agreed form over the relevant period without the need to review the details of the expenditure or determine whether such expenditure would have been met by that body, together with interest;

f) An agreement to refer disputes to mediation (possibly with an independent legal view being provided if that is needed) if the dispute cannot be resolved by this process.

9.8 The CCG has a duty agree procedures for seeking to resolve the dispute once it has arisen. This could involve agreeing a dispute resolution process with the local social services authority in advance of a dispute or could involve a "one-off" procedure once a dispute has arisen. There are many CCGs and local authorities where protocols are not in place between CCGs and local authorities. There are many model policies in existence but the Sheffield CCG dispute resolution policy is an example of one which is straightforward and sensible.

9.9 The guidance does not specifically explain what happens if the CCG and the local authority have not been able to agree local dispute resolution protocols as has happened in a number of areas. In those circumstances, there is probably a duty on

the CCG to offer a form of mediation. However, as the Court of Appeal made clear in *St Helens Borough Council v Manchester Primary Care Trust & Anor*[41] [2008] EWCA Civ 931, the NHS commissioning body is the ultimate decision maker and its decision will only be set aside if the court considers that it is a *Wednesbury* unreasonable decision.

10 **What package of NHS funded services should be provided to a CHC eligible patient?**

10.1 The CCG has two different types of decision to make:

a) Does the patient qualify for CHC; and

b) If the patient does qualify, what package of support should be provided by the CCG and others including the local authority to support the patient.

10.2 Once the CCG has made the decision that the patient is eligible for CHC, the CCG comes under a legal duty to offer an appropriate package of services to meet the patient's needs for medical services, social care services and accommodation (where that is part of the need). This duty is explained in paragraphs 108 to 111 of the National Framework which provide:

> "108. Where an individual is eligible for NHS continuing healthcare, the CCG is responsible for care planning, commissioning services and for case management. It is the responsibility of the CCG to plan strategically, specify outcomes and procure services, to manage demand and provider performance for all services that are required to meet the needs of all individuals who qualify for NHS continuing healthcare, and for the healthcare part of a joint care package. The services commissioned must include ongoing case management for all those entitled to NHS continuing healthcare, as well as for the NHS elements of joint packages, including review and/or reassessment of the individual's needs.
>
> 109. As with all service contracts, commissioners are responsible for monitoring quality, access and patient experience within the context of provider performance.

[4141] http://www.bailii.org/ew/cases/EWCA/Civ/2008/931.html [should just be fn 9 not 99]

This is particularly important in this instance, as ultimate responsibility for arranging and monitoring the services required to meet the needs of those who qualify for NHS continuing healthcare rests with the CCG. CCGs should ensure that there is clarity on the respective responsibilities of commissioners and providers with regard to NHS continuing healthcare.

110. CCGs should take a strategic as well as an individual approach to fulfilling their NHS continuing healthcare commissioning responsibilities. CCGs may wish to commission NHS-funded care from a wide range of providers, in order to secure high-quality services that offer value for money. As part of their joint commissioning responsibility, CCGs and LAs should work in partnership, and share information (where reasonable) to enable them to commission the most appropriate packages of care for their populations.

111. Many individuals in receipt of NHS continuing healthcare and joint care packages will have long-term conditions. CCGs and LAs should take into account the policy set out in Supporting People with Long Term Conditions: Commissioning Personalised Care Planning20.The approaches set out may also be helpful in care planning for those in receipt of NHS continuing healthcare who do not have a long-term condition. The individual and personalised approaches described in Valuing People Now for people with learning disabilities are similarly relevant. Care planning for needs to be met under NHS continuing healthcare should not be carried out in isolation from care planning to meet other needs, and, wherever possible, a single, integrated and personalised care plan should be developed.

See also paragraphs 166 - 171 below regarding commissioning and personalisation"

10.3 There is further guidance on care planning at paragraphs 166-7 which provides:

"166. Whether or not a person is eligible for NHS continuing healthcare, if they have ongoing care needs, the care planning process helps in the decision on how best to meet those needs.

167. Where a person qualifies for NHS continuing healthcare, the package to be provided is that which the CCG assesses is appropriate to meet all of the individual's assessed health and associated social care needs. Although the CCG is not bound by the views of the LA on what services the individual requires, the LA's assessment under section 47 of the National Health Service and Community Care Act 1990, or its

contribution to a joint assessment, will be important in identifying the individual's needs and, in some cases, the options available for meeting them"

10.4 This guidance is expanded at PG4 (pages 53-55 of the National Framework). PG also provides:

PG 78 How should care planning be approached for a person entitled to NHS continuing healthcare?

78.1 It is important that the services commissioned and provided for a person in receipt of NHS continuing healthcare are based on supporting the outcomes identified in a care plan jointly developed and agreed with the individual and regularly updated and reviewed. There should therefore be strong linkages between the care planning and 02 commissioning processes in CCGs.

78.2 Supporting People with Long-Term Conditions; Commissioning Personalised Care Planning. A Guide for Commissioners sets out how to adopt a personalised approach for individuals with a long-term condition and how to reflect this in the commissioning of services. Clearly most people who are eligible for NHS continuing healthcare have a long-term condition or other long-term health need. Even for those who qualify for other reasons, the approaches in the guidance are still applicable. It sets out that the care planning process:

- puts the individual, their needs and choices that will support them to achieve optimal health and well-being at the centre of the process
- focuses on goal setting and outcomes that people want to achieve, including carers
- is planned, anticipatory and proactive with contingency planning to manage crisis episodes better
- promotes choice and control by putting the person at the centre of the process and facilitating better management of risk
- ensures that people, especially those with more complex needs, the socially excluded and particularly vulnerable or those approaching the end of life, receive coordinated care packages, reducing fragmentation between services

- provides information that is relevant and timely to support people with decision-making and choices

- provides support for self care so that people can self care/self manage their condition(s) and prevent deterioration

- facilitates joined-up working between different professions and agencies, especially between health and social care, and

- results in an overarching, single care plan that is owned by the person but can be accessed by those providing direct care/services or other relevant people as agreed by the individual, e.g. their carer(s). The important aspect of this is that the care planning discussion has taken place with an emphasis on goal setting, equal partnership, negotiation and shared decision-making.

78.3 There are other models of personalised care planning using similar approaches which could also be used when appropriate"

10.5 These are patients with complex and unpredictable needs, many of whom will require a bespoke package of services. Thus the CCG needs to undertake active case management to ensure that the services that are provided are suitable to meet the patient's reasonable requirements. This case management duty is explained at PG 80[42] and the commissioning responsibilities at PG 80. These provide:

"PG 80 Case management

80.1 Once an individual has been found eligible for NHS continuing healthcare, the CCG is responsible for their case management, including monitoring the care they receive and arranging regular reviews. This could be through joint arrangements with LAs, subject to local agreement. CCGs should ensure arrangements are in place for an ongoing case management role for all those entitled to NHS continuing healthcare, as well as for the NHS elements of joint packages.

80.2 Case management should be person-centred. The individual should be encouraged to have an active role in their care, be provided with information or signposting to enable informed choices, and supported to make their own decisions.

[42] Page 104 of the National Framework.

80.3 In the context of NHS continuing healthcare case management necessarily entails management of the whole package, not just the healthcare aspects. The key elements of the role include:

a) ensuring that a suitable care plan has been drawn up for and with the individual in line with the approaches set out in PG 78 above – this might best be done initially by the MDT involved in their care, in consultation with the person concerned or their representative

b) ensuring that the care/support package meets the individual's assessed needs and agreed outcomes and is appropriate to achieve the identified intended outcomes in the care plan

c) where the care plan includes access to non-NHS services, for example leisure services, ensuring that the arrangements for these are in place and are working effectively

d) monitoring the quality of the care and support arrangements and responding to any difficulties/concerns about these in a timely manner

e) acting as a link person to coordinate services for the individual

f) ensuring that any changes in the person's needs are addressed

g) reviewing the situation on a regular planned basis, and if necessary undertaking additional unplanned reviews where circumstances require. Reviews need to consider not just whether the individual is still eligible for NHS continuing healthcare but also the effectiveness and appropriateness of the care/support arrangements.

PG 81How should commissioning be approached for a person entitled to NHS continuing healthcare?

81.1 This Framework sets out a number of responsibilities of CCGs in relation to NHS continuing healthcare commissioning:

a) NHS continuing healthcare commissioning involves actions at both strategic and individual levels.

b) NHS continuing healthcare commissioning actions by CCGs should include strategic planning, specifying outcomes, procuring services, and managing demand and provider performance (including monitoring quality, access and the experience of those in receipt of NHS continuing healthcare). In managing the quality and performance of providers and the experiences of those using their services, CCGs should take into account the role and areas of focus of the Care Quality Commission and, where relevant, LA commissioners of the relevant provider's services in order to avoid duplication and to support the mutual development of an overall picture of each provider's performance.

c) There should be clarity on the roles of commissioners and providers. The services commissioned should include an ongoing case management role as well as the assessment and review of individual needs.

d) CCGs should consider commissioning from a wide range of providers in order to secure high quality, value for money services. In exercising this responsibility, CCGs should have regard to the case management role set out in 11.4 above of ensuring that the care/support package meets the individual's assessed needs and agreed outcomes and is appropriate to achieve the identified intended outcomes in the care plan. To help inform this approach, CCGs should have an understanding of the market costs for care and support within the relevant local area.

e) CCGs should commission in partnership with LAs wherever appropriate.

f) CCGs should ensure clarity regarding the services being commissioned from providers, bearing in mind that those in receipt of NHS continuing healthcare continue to be entitled to access the full range of primary, community, secondary and other health services. The services that a provider of NHS continuing healthcare-funded services is expected to supply should be clearly set out in the contract between the provider and the CCG. CCGs should commission services using models that maximise personalisation and individual control and that reflect the individual's preferences as far as possible. It is particularly important that this approach should be taken when an individual who was previously in receipt of an LA direct payment begins to receive NHS continuing healthcare; otherwise they may experience a loss of the control they had previously exercised over their care. CCGs should also be aware of the personal health budgets programme as set out in Personal Health Budgets: First Steps

44 and particularly that it is only direct payments that will be restricted to approved pilots. The other models of personal health budgets are available under existing powers for any CCG to use.

g) CCGs and LAs should operate person-centred commissioning and procurement arrangements, so that unnecessary changes of provider or of care package do not take place purely because the responsible commissioner has changed.

h) CCGs should take into account other policies and guidance relevant to the individual's needs"

10.6 However, CCGs also need to bear in mind that these services need to be subject to strict cost-effectiveness tests in the same way as the provision of all other NHS services are subject to such tests. Once a CCG has reached a decision that a patient is eligible for CHC, it is necessary for the CCG to decide what services should be provided to support the patient. Eligibility for CHC is not a "blank cheque" which means that every one of the patient's social and healthcare needs are required to be met by the NHS.

Funding for aids and adaptations.

10.7 PG 79 provides the following guidance about funding aids and adaptations for a person who is eligible for CHC:

"PG 79 Who is responsible for equipment and adaptations if someone is eligible for NHS continuing healthcare and is in their own home?

79.1 The focus of NHS continuing healthcare should be on enabling the delivery of the desired outcomes of the individual and promoting their physical and psychological well-being. Care planning should therefore consider the need for equipment to assist with activities of daily living and the provision of healthcare, personal care, social care support and wider housing adaptation needs.

79.2 As set out in the Framework (paragraph 172), those in receipt of NHS continuing healthcare should have access to local joint equipment services on the same basis as any other patient of their CCG. Local agreements on the funding of joint equipment

services should take into account the fact that the NHS has specific responsibilities for meeting the support needs of those entitled to NHS continuing healthcare. Some individuals will require bespoke equipment (and/or specialist or other non-bespoke equipment that is not available through joint equipment services) to meet specific assessed needs identified in their NHS continuing healthcare care plan. CCGs should make appropriate arrangements to meet these needs.

79.3 For larger adaptations, Disabled Facilities Grants (DFGs) may be available from local housing authorities towards the cost of housing adaptations that are necessary to enable a person to remain living in their home (or to make a new home appropriately accessible). DFGs are means-tested. However, housing authorities, CCGs and LA social services authorities all have discretionary powers to provide additional support where appropriate. Further details can be found in the guidance Delivering Housing Adaptations for Disabled People; A Good Practice Guide43. This guidance encourages the above bodies, together with home improvement agencies and registered social landlords, to work together locally on integrated adaptations services. Whether or not such integrated services are in place, CCGs should consider having clear arrangements with partners setting out how the adaptation needs of those entitled to NHS continuing healthcare should be met, including referral processes and funding responsibilities.

79.4 CCGs should be aware of their responsibilities and powers to meet housing-related needs for those entitled to NHS continuing healthcare:

> a) CCGs have a general responsibility under section 3(1)(e) of the NHS Act 2006 to provide such after-care services and facilities as it considers appropriate as part of the health service for those who have suffered from illness.
>
> b) The Board has responsibility for arranging, under section 3B(1) of the NHS Act 2006 and under Standing Rules Regulations, secondary care and community services for serving members of the armed forces and their families, and prisoners, as part of the health service to such an extent as it considers necessary to meet all reasonable requirements.
>
> c) CCGs may make payments in connection with the provision of housing to housing authorities, social landlords, voluntary organisations and certain other bodies under sections 256 and 257 of the above Act.

d) CCGs also have a more general power to make payments to LAs towards expenditure incurred by the LA in connection with the performance of any LA function that has an effect on the health of any individual, has an effect on any NHS function, is affected by any NHS function or are connected with any NHS function.

e) Housing can form part of wider partnership arrangements under section 75 of the above Act.

79.5 LAs should be aware that they may continue to have responsibilities under section 47 of the NHS and Community Care Act 1990 and under section 2 of the Chronically Sick and Disabled Persons Act 1970 to those in receipt of NHS continuing healthcare. However, in deciding whether it is necessary to provide services under these provisions the LA should take into account services that are/will be provided by the NHS, either as NHS 04 continuing healthcare or as other NHS services. They may also continue to have some responsibilities for those in their own homes entitled to NHS continuing healthcare where the services needed are not ones that the Secretary of State requires the NHS to provide. This can include support for housing-related needs where appropriate. When carrying out an assessment for a property adaptation or the provision of equipment for someone receiving NHS continuing healthcare funding, LAs should respond positively to requests for a community occupational therapy assessment to assist and advise the individual and the CCG on deciding on appropriate equipment/adaptation and whether or not the adaptation is necessary to meet the assessed NHS continuing healthcare needs.

79.6 Whilst LAs and CCGs have some overlapping powers and responsibilities in relation to supporting individuals eligible for NHS continuing healthcare in their own home, a reasonable division of responsibility should be negotiated locally. In doing this, CCGs should be mindful that their responsibility under NHS continuing healthcare involves meeting both health and social care needs based on those identified through the MDT assessment. Therefore, whilst LAs and CCGs have overlapping powers, in determining responsibilities in an individual case, CCGs should first consider whether the responsibility to meet a specific need lies with them as part of their NHS continuing healthcare responsibilities. LAs should be mindful of the types of support that they may provide in such situations as outlined in PG85 below"

Choice of accommodation

10.8 Although some patients who are eligible for CHC are supported in their own homes, many patients need to be provided with accommodation as part a package of

services. It is good practice for CCG policies to cover the issue of choice of accommodation and some CCGs follow the scheme set out in Annex A to the Statutory Guidance under the Care Act 2014[43]. However, the patient's choice must be subject to certain conditions. Some Guidance on this is provided at PG 83 which provides:

"PG 83What limits (if any) can be put on individual choice where, if followed, this would result in a CCG paying for a very expensive care arrangement? Under what circumstances can a CCG decline to provide care in the preferred setting of the individual?

83.1 This Framework says (paragraph 167) that 'the package to be provided is that which the CCG assesses is appropriate for the individual's needs'.

83.2 In many circumstances there will be a range of options for packages of support and their settings that will be appropriate for the individual's needs. The starting point for agreeing the package and the setting where NHS continuing healthcare services are to be provided should be the individual's preferences. Individuals will not always be aware of the models of support that it is possible to deliver (for example, they may assume that it is only possible to receive support in a care home). Those involved in working with individuals to plan their future support should advise them of the options and the benefits and risks associated with each one. CCGs should be aware of the models of support offered by partners and in the case of CCGs, by other CCGs, and of evidence about their benefits and risks so that the options offered are maximised and that generalised assumptions are avoided.

83.3 In some situations a model of support preferred by the individual will be more expensive than other options. CCGs can take comparative costs and value for money into account when determining the model of support to be provided but should consider the following factors when doing so:

a) The cost comparison has to be on the basis of the genuine costs of alternative models. A comparison with the cost of supporting a person in a care home should be based on the actual costs that would be incurred in supporting a person with the specific needs in the case and not on an assumed standard care home cost.

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[43] See https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf

b) Where a person prefers to be supported in their own home, the actual costs of doing this should be identified on the basis of the individual's assessed needs and agreed desired outcomes. For example, individuals can sometimes be described as needing 24-hour care when what is meant is that they need ready access to support and/or supervision. CCGs should consider whether models such as assistive technology could meet some of these needs. Where individuals are assessed as requiring nursing care, CCGs should identify whether their needs require the actual presence of a nurse at all times or whether the needs are for qualified nursing staff or specific tasks or to provide overall supervision. The willingness of family members to supplement support should also be taken into account, although no pressure should be put on them to offer such support. CCGs should not make assumptions about any individual, group or community being available to care for family members.

c) Cost has to be balanced against other factors in the individual case, such as an individual's desire to continue to live in a family environment (see the Gunter case in box below)"

10.9 There is reference in the Guidance to the Gunter case at PG 84 which states:

"84.1 In the case of *Gunter vs. South Western Staffordshire Primary Care Trust* (2005), a severely disabled woman wished to continue living with her parents whereas the PCT's preference was for her to move into a care home. Whilst not reaching a final decision on the course of action to be taken, the court found that Article 8 of the European Convention of Human Rights had considerable weight in the decision to be made, that to remove her from her family home was an obvious interference with family life and so must be justified as proportionate. Cost could be taken into account but the improvement in the young woman's condition, the quality of life in her family environment and her express view that she did not want to move were all important factors which suggested that removing her from her home would require clear justification"

10.10 However that decision did not reach a definitive conclusion and probably needs to be seen in the light of the later Court of Appeal case of *R (Condliff) v North Staffordshire Primary Care Trust* [2011] EWCA Civ 910 [2012] PTSR 460[44] which decided that article

[44] See http://www.bailii.org/ew/cases/EWCA/Civ/2011/910.html

8 rights were not engaged in NHS commissioning decisions where those decisions were based on the allocation of resources.

10.11 A number of CCGs have policies which set up a series of conditions for considering choice of accommodation for CHC patients which CCGs may wish to adopt along the following lines:

a) Having regard to the CQC registration and inspection reports, does the preferred accommodation appear to the CCG to be suitable in relation to the patient's needs as assessed by the CCG?

b) Would the cost of making arrangements for the patient at the preferred accommodation require the CCG to pay more than they would usually expect to pay having regard to the patient's assessed needs?

c) Is the preferred accommodation available?

d) Are the persons in charge of the preferred accommodation willing and able to provide it to the patient subject to the CCG usual terms and conditions, having regard to the nature of the accommodation, for providing accommodation for such a person for NHS Continuing Healthcare?

10.12 If the above approach is followed, CCG policies provide that the CCG usually place the patient in his or her preferred care home. This could be in another part of the UK if, for example, the patient has reached a stage in life where their priority is to live near a relative.

10.13 The patient's article 8 rights are probably, to a limited degree, engaged in any placement decision making process, and so the CCG would only be entitled to insist on being placed in another care home if the preferred care home failed the above

tests. There is a particular problem where a patient is living in a care home where the fees are higher than the CCG considers that it ought to pay to provide services to the patient. The CCG may offer of a package of services for the patient at a different and less expensive home and thus discharge its statutory duty. Patients are not obliged to accept NHS services and the CCG discharges its duties to a patient if it makes an offer of a package of services, including accommodation, to a patient.

10.14 There does not appear to be any legal presumption that a care package for a CHC eligible patient should enable a patient to remain in their present home. Contrary to the position taken by the Equality and Human rights Commission, it is hard to see that the patient's rights under Article 8 of the European Convention on Human Rights imposes an obligation on a CCG to spend significantly more of its resources to support a patient in his or her own home than offering to fund a package of care for the patient in a suitable care setting. Whilst the preferences of the patient are an important factor which the CCG needs to take into account in making the overall decision, cost is also a key factor: see *Gunter v. South Western Staffordshire PCT* [2005] EWHC 1894 (Admin)[45].

10.15 This is a complex and contentious area, and it would be helpful if CCG policies, endorsed by the CCG Governing Body, made this policy position clear from the outset. CCGs need to ensure that there is a measure of equity in the levels investment provided by the CCG in supporting different groups of patients. This can therefore mean that:

a) The CCG offers to discharge its duty by providing a package of services for a patient in a care or nursing home which is not their preferred home. The CCG offers to discharge its duty to a patient who, to date, has had a package of services in their own home by moving the patient to a care home (since the

[45] See http://www.bailii.org/ew/cases/EWHC/Admin/2005/1894.html

costs of providing such care may be significantly less than providing care for an isolated individual patient); or

b) The CCG offers to provide a package of domiciliary care services in the patient's own home which is the same broad cost of a package of services in a care home and either (i) the patient funds the provision of other services from his own resources, which can typically be a personal injury pay-out, (ii) relatives or family members agree to provide additional support to fill any gaps left by NHS provision which is not being provided or (iii) the patient is content to accept a service which is less than required to meet his assessed needs but prefers to accept such a package than move to a care home.

10.16 If agreement cannot be reached with the patient on a package of domiciliary care services in the patient's own home and the CCG continues to offer a care home placement that the patient refuses, the CCG will discharge its legal duties to the patient by offering the care home placement (albeit that this placement is refused). In such circumstances the CCG can lawfully withdraw an existing package of domiciliary care services in the patient's own home.

No top up fees or fee sharing for NHS services.

10.17 One a key difference between NHS and social services care appears to be that there is no provision within the NHS for cost sharing or for families to provide top up fees to augment the cost of a care home package in the individual's chosen care home if that is higher than the cost of a package at a care home that the CCG is prepared to fund. The reason for this difference is that NHS services are required to be provided free of charge and thus the traditional view is that fee sharing is not permissible for core NHS services[46]. The NHS Choices website[47] explains:

[46] See section 1(3) of the National Health Service Act 2006.
[47] See http://www.nhs.uk/conditions/social-care-and-support-guide/pages/nhs-continuing-care.aspx

"Is it possible to pay top-up fees for NHS continuing healthcare?

No, it is not possible to top up NHS continuing healthcare packages, like you can with local authority care packages.

The only way that NHS continuing healthcare packages can be topped up privately is if you pay for additional private services on top of the services you get from the NHS. These private services should be provided by different staff and preferably in a different setting"

10.18 Guidance on this is provided at PG 96 and PG 99 which provide:

"PG 96 Can an individual pay for additional services themselves in addition to their NHS continuing healthcare package?

96.1 DH published guidance (referred to below as the 'Additional Private Care guidance') in March 2009 on NHS patients who wish to pay for additional private care, in addition to their NHS care package. Although it is primarily aimed at situations where NHS patients want to buy additional secondary and specialist care services that the NHS doesn't fund, it contains a set of principles applicable to all NHS services:

a) As affirmed by the NHS Constitution:

- the NHS provides a comprehensive service, available to all
- access to NHS services is based on clinical need, not an individual's ability to pay, and
- public funds for healthcare will be devoted solely to the benefit of the people that the NHS serves.

b) The fact that some NHS patients also receive private care separately should never be used as a means of downgrading or reducing the level of service that the NHS offers. NHS organisations should not withdraw any NHS care simply because a patient chooses to buy additional private care.

c) As overriding rules, it is essential that:

- the NHS should never subsidise private care with public money, which would breach core NHS principles, and

- patients should never be charged for their NHS care, or be allowed to pay towards an NHS service (except where specific legislation is in place to allow this) as this would contravene the founding principles and legislation of the NHS.

96.2 To avoid these risks, there should be as clear a separation as possible between private and NHS care.

96.3 CCGs should seek to ensure that providers are aware of the above principles. Where a provider receives a request for additional privately-funded services from an individual who is funded by NHS continuing healthcare they should refer the matter to the CCG for consideration.

96.4 The following specific issues should be considered when dealing with additional private care issues in relation to NHS continuing healthcare:

- The NHS care package provided should be based on the individual's health and social care needs as identified in their care plan, developed from the multidisciplinary assessment in the NHS continuing healthcare eligibility process (including any changes to the care plan following review of the individual's needs).

- The care plan should set out the services to be funded and/or provided by the NHS. It may also identify services to be provided by other organisations such as LAs but the NHS element of the care should always be clearly identified. Any care which would normally have provided in the course of good NHS practice should continue to be offered free of charge on the NHS.

- Where an individual advises that they wish to purchase additional private care or services, CCGs should discuss the matter with the individual to seek to identify the reasons for this. If the individual advises that they have concerns that the existing care package is not sufficient or not appropriate to meet their needs, CCGs should offer to review the care package in order to identify whether a different package would more appropriately meet the individual's assessed needs.

- CCGs should also be aware that individuals in receipt of NHS continuing healthcare continue to be eligible for all other services available to patients of their CCG. In developing or reviewing care packages, CCGs should consider whether other services commissioned or provided by the CCG would help meet the individual's needs.

- The decision to purchase additional private care services should always be a voluntary one for the individual. Providers should not require the individual to purchase additional private care services as a condition of providing, or continuing to provide, NHS-funded services to them.

- In the Additional Private Care guidance, 'separation' is defined as usually requiring the privately-funded care to take place in a different location and at a different time to the NHS-funded care. However, many individuals eligible for NHS continuing healthcare have limitations on their ability to leave their home due to their health needs. Moreover, the majority of the care they receive is often by its nature focused on supporting them within their own home and any additional private care may well also be focused on home-based support. Therefore, although the principle of separation still applies to NHS continuing healthcare, a different approach may be necessary. For example, where a person receives 24-hour NHS-funded support by way of a care home package it may not be possible for privately-funded care to be provided at a time that is separate to NHS-funded care. However, in such circumstances, the private care should be delivered by different staff to those involved in delivering the NHS-funded care at the time it takes place and they should not be delivering treatment, care or support identified within the care plan as being part of the NHS-funded service.

- Although NHS-funded services must never be reduced or downgraded to take account of privately-funded care, the CCG and the organisations delivering NHS-funded care should, wherever clinically appropriate, liaise with those delivering privately-funded care in order to ensure safe and effective coordination between the services provided. Transfers of responsibility between privately-funded and NHS care should be carried out in a way which avoids putting individuals receiving services at any unnecessary risk. The CCG, the NHS-funded provider and the privately-funded provider should work collaboratively to put in place protocols to ensure effective risk management, timely sharing of information, continuity of care and coordination between NHS-funded and privately-funded care at all times. If different staff are involved in each element of care, these protocols should include arrangements

for the safe and effective handover of the patient between those in charge of the NHS care, and those in charge of the privately-funded care.

- As when patients are transferred from one NHS organisation to another, it should always be clear which clinician/care provider staff and which organisation is responsible for the assessment of the patient, the delivery of any care and the delivery of any follow-up care"

PG 99Can an individual 'top-up' their care package to pay for higher-cost services or accommodation?

99.1 The funding provided by CCGs in NHS continuing healthcare packages should be sufficient to meet the needs identified in the care plan, based on the CCG's knowledge of the costs of services for the relevant needs in the locality where they are to be provided. It is also important that the models of support and the provider used are appropriate to the individual's needs and have the confidence of the person receiving the services.

99.2 Unless it is possible to separately identify and deliver the NHS-funded elements of the service, it will not usually be permissible for individuals to pay for higher-cost services and/or accommodation (as distinct from purchasing additional services). However, there may be circumstances where the CCG should consider the case for paying a higher-than-usual cost. For example, where an individual indicates a desire to pay for higher-cost accommodation or services, the relevant CCG should liaise with them to identify the reasons for the preference. Where the need is for identified clinical reasons (for example, an individual with challenging behaviour wishes to have a larger room because it is identified that the behaviour is linked to feeling confined, or an individual considers that they would benefit from a care provider with specialist skills rather than a generic care provider), consideration should be given as to whether it would be appropriate for the CCG to meet this.

99.3 In some circumstances individuals become eligible for NHS continuing healthcare when they are already resident in care home accommodation for which the fees are higher than the relevant CCG would usually meet for someone with their needs. This may be where the individual was previously funding their own care or where they were previously funded by an LA and a third party had 'topped up' the fees payable. 'Topping- up' is legally permissible under legislation governing LA social care but is not permissible under NHS legislation. For this reason, there are some circumstances where a CCG may propose a move to different accommodation or a change in care provision.

99.4 In such situations, CCGs should consider whether there are reasons why they should meet the full cost of the care package, notwithstanding that it is at a higher rate, such as that the frailty, mental health needs or other relevant needs of the individual mean that a move to other accommodation could involve significant risk to their health and well-being.

99.5 There may also be circumstances where an individual in an existing out of area placement becomes entitled to NHS continuing healthcare and where, although the care package is of a higher cost than the responsible CCG would usually meet for the person's needs, the cost is reasonable taking into account the market rates in the locality of the placement. CCGs should establish this by liaison with the CCG where the placement is located. In such circumstances CCGs should consider whether there are particular circumstances that make it reasonable to fund the higher rate. This could be because the location of the placement is close to family members who play an active role in the life of the individual or because the individual has resided in the placement for many years so that they have strong social links with the area and it would be significantly detrimental to the individual to move them.

99.6 CCGs should deal with the above situations with sensitivity and in close liaison with the individuals affected and, where appropriate, their families, the existing service provider and the local authority if they have up to this point been funding the care package. Where a CCG determines that circumstances do not justify them funding an existing higher cost placement or services that they have inherited responsibility for, any decisions on moves to other accommodation or changes in care provider should be taken in full consultation with the individual concerned and put in writing with reasons given. Advocacy support should be provided where this is appropriate.

99.7 Where an individual become entitled to NHS continuing healthcare and has an existing high-cost care package, CCGs should consider funding the full cost of the existing higher-cost package until a decision is made on whether to meet the higher cost package on an ongoing basis or to arrange an alternative placement.

99.8 Where separation of NHS and privately funded care arrangements is possible, the financial arrangements for the privately funded care is entirely a matter between the individual and the relevant provider and it should not form part of any service agreement between the CCG and the provider.

99.9 Where an individual wishes to dispute a decision not to pay for higher-cost accommodation, they should do this via the NHS complaints process. The letter from the CCG advising them of the decision should also include details of the complaints process and who to contact if the individual wishes to make a complaint.

99.10 The new accommodation and/or services should reflect the individual's assessed needs as identified in their care plan, including taking into account personal needs such as proximity to family members. Individuals should be provided with a reasonable choice of 119 providers. A transition care plan should be developed by the existing and new providers that identifies key needs and preferences, including how any specific needs and risks in the transition process should be addressed. The CCG should keep in regular liaison with the new provider and with the individual during the initial weeks of the new services to ensure that the transition has proceeded successfully and to ensure that any issues that have arisen are being appropriately addressed.

99.11 Further details are given in Personal Health Budgets: First Steps"

10.19 This Guidance is potentially confusing and may not be wholly consistent. It is an area where CCGs should bear in mind that patients have a right to use their own money as they wish and that interferences with that right under article 1 of protocol 1 of the ECHR have to justified. So this is, perhaps, "guidance" which should be treated lightly.

10.20 It is clearly permissible for the patient or relatives to agree a package of additional services with the care home owners (such as a visits from a chiropodist, hairdresser or even to pay for a larger room). See for example *S v Dudley PCT* [2009] EWHC 1780 (Admin)[48]. However, in order to comply with NHS Guidance, the CCG ought to be able to enter into a contract with the home owners which is capable of standing on its own without the support of others.

10.21 The absence of a fee sharing arrangement can lead to significant difficulties where a patient has chosen a social care setting in circumstances where patient or relatives

[48] This case is reported on Lawtel and LexisNexis but not in any open source website.

are making a contribution towards the cost. This can either supplement the sums paid by the local authority or may represent the whole of the cost. A change from local authority/patient funding to NHS funding can then arise where and the patient's medical condition deteriorates, the patient becomes eligible for CHC. In such a case, the CCG may be offered to discharge its obligations by funding care for the patient at a less expensive care home.

10.22 There are 2 potential routes a patient could take to avoid having to make the choice between continuing to pay the fees in their existing care home or moving to a less expensive care home. These are:

a) Asking for a personal health budget to meet the costs of the care that the individual needs. The budget would be set at the costs of the less expensive care home, but the patient could then use their own money to use the funds to purchase care at the more expensive care home; or

b) The more expensive care home could divide its offer of services into 2 separate contracts; one for the accommodation costs and the other for care services. CHC only meets accommodation costs if the patient has a "need" for the NHS to pay for accommodation. A CHC patient in their own home does not have the rent or mortgage paid by the NHS. Accordingly, a care home which created a separate "accommodation contract" could allow the patient to argue that he or she had no accommodation needs, and that it was therefore cost-effective for the CCG to purchase care services from his existing care home.

10.23 There is no established case law to demonstrate that either of these approaches will be successful and any patient seeking to use these arrangements would be well advised to seek individual legal advice.

11 Contracting with care homes and other providers of care under CHC

11.1 If the CCG agrees to provide care to a patient at a care home, a written contract in the form of an NHS Standard Contract should be entered into between care home and the CCG. CCGs are under a statutory duty to use the NHS Standard Contract: see part 5 of the 2012 Regulations and the NHS England Technical Guidance[49].

11.2 The contract should set out the level of service that the home agrees to provide, define clinical governance regimes, review mechanisms and the price to be paid. It should limit the extent to which the care home can increase the fees and require the care home to report to the CCG if the patient's medical condition changes. From April 2016, CCGs have been permitted to use the Shorter Form Contract[50]. However, this contract is still 70 pages long and so is only "shorter" than the full contract that runs to over 200 pages.

12 Direct Payments for CHC patients.

12.1 Patients who have long term conditions which require support from either the NHS or social services are entitled to have sums paid to them and then, in effect, to purchase and arrange their own care under a system of direct payments. PG 90[51] provides the following guidance about the use of direct payments:

> **"PG 90Can a personal health budget be used for people eligible for NHS continuing healthcare?**
>
> 90.1 Yes, CCGs are encouraged to use personal health budgets where appropriate .A personal health budget helps people to get the services they need to achieve their health outcomes, by letting them take as much control over how money is spent on their care/support as is appropriate for them. It does not necessarily mean giving them the money itself. Personal health budgets could work in a number of ways, including:
>
> - a notional budget held by the CCG commissioner

[49] See https://www.england.nhs.uk/nhs-standard-contract/16-17/
[50] See https://www.england.nhs.uk/wp-content/uploads/2016/04/nhse-contrcts-shrt-frm-guid.pdf

- a budget managed on the individual's behalf by a third party, and

- a cash payment to the individual (a 'healthcare direct payment').

90.2 Direct payments for healthcare can only currently be offered by the Board, or by CCGs that are pilot sites approved by the Secretary of State. However CCGs already have powers to offer other forms of personal health budgets, either as a notional budget or a real budget held by a third party.

Further details are given in Personal Health Budgets: First Steps"

12.2 The system for NHS direct payments is now governed by the National Health Service (Direct Payments) Regulations 2013 (as amended by the National Health Service (Direct Payments) (Amendment) Regulations 2013). Readers are referred to separate chapter about direct payments and the inter-relationship between CHC and direct payments is considered in that chapter.

12.3 Direct payments can often deliver value for money to the local authority, properly reward members of the family who provide voluntary care and give control to patients and their families. It can result in carers being directly employed by the service user. Patients who are entitled to CHC are entitled to seek a direct payment from April 2014[52]. The amount of the direct payment must be:

"sufficient to provide for the full cost of each of the services specified in the care plan"

12.4 It is hard to see how a direct payment can be appropriate where a CHC patient is accommodated in a care home save where this is part of an arrangement to enable a patient to remain in a care home of their own choice. However direct payments can be used by CHC eligible patients who live in their own homes or in supported living.

[51] See page 110 of the National Framework.
[52] This is explained in the statutory guidance which is at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf

13 Providing a care package into a patient's own home.

13.1 If the patient is to be provided with a care package in his own home, the details of the care to be provided should be set out clearly in a care plan which describes the level of service to be provided to the patient and how it is to be delivered. CCGs are entitled to contract out such care packages to domiciliary care providers. If this happens, the CCG should ensure there is an NHS Standard Contract (possibly in the shorter form) between the domiciliary care provider and the CCG which covers the same areas as a contract with a care home (See above). Guidance on this is provided in PG 85 which provides:

> **"PG 85 What are the responsibilities of CCGs and LAs when a person is supported in their own home?**
>
> 85.1 Where someone is assessed as eligible for NHS continuing healthcare but chooses to live in their own home in order to enjoy a greater level of independence, the expectation in the Framework is that the CCG would remain financially responsible for all health and personal care services and associated social care services to support assessed health and social care needs and identified outcomes for that person, e.g. equipment provision (see PG 79), routine and incontinence laundry, daily domestic tasks such as food preparation, shopping, washing up, bed-making, support to access community facilities, etc. (including additional support needs for the individual whilst the carer has a break). However, people who choose to live in their own home may have additional community care needs which it may be appropriate for the LA to address subject to their local eligibility threshold and charging policy, e.g. assistance with property adaptation (see PG 79), support with essential parenting activities, support to access other community facilities, carer support services that may include additional general domestic support, or indeed any appropriate service that is specifically required to enable the carer to maintain his/her caring responsibilities (bearing in mind PG 89 below).
>
> 85.2 There is a range of circumstances in which CCGs have overlapping powers with other statutory organisations. Where this is the case, CCGs and other statutory bodies should work in partnership locally to determine how each partner's responsibilities will be exercised. CCGs should not simply assume that another organisation will meet the need. Active liaison should take place. The needs appropriate for the CCG to meet will depend upon the circumstances of the individual case, having regard to the overall

purpose of the health service – to improve physical or mental health, and to prevent, diagnose or treat illness.

85.3 Where other agencies/organisations have potentially overlapping powers/ responsibilities there should be a discussion between the parties involved. If someone is receiving NHS continuing healthcare in their own home their benefits are unaffected (although they will not be able to receive support from the Independent Living Fund). There is a range of everyday household costs that are expected to be covered by personal income or through welfare benefits (i.e. food, rent/mortgage interest, fuel, clothing and other normal household items). In addition, disability-related benefits (e.g. Disability Living Allowance and Attendance Allowance) are intended to cover some disability-related costs. As individual circumstances will differ considerably, it is not possible to give hard and fast rules on how best to divide responsibilities where overlapping powers exist. However, the following questions may help inform the decision-making process:

a) Is this service part of the support plan necessary to meet the individual's assessed health, personal care and associated social care needs?

b) What support is necessary for the CCG to fund/provide in order for the individual to access essential services?

c) What responsibilities do other organisations/agencies have to enable the person to access essential services?

d) What would happen if a CCG or a partner organisation did not fund/ provide the service in question – what would the outcome be?"

13.2 Where the CCG delivers care using its own staff, it needs a clear policy about the approach to be taken by its staff in designing packages to support patients in their own homes. Whilst there can be enormous merit for both the patient and the CCG in maintaining the patient at home (and the CCG does not need to pay for accommodation costs) as patients with chronic conditions require an increasing level of services there can come a time when the overall cost of the package is substantially higher than providing services to patients in a nursing home. There can also be significant problems with sustaining staff in a home if there are continuous disagreements between carers and the patient and/or their family.

13.3 The CCG needs to be mindful that, if it is using its own staff to deliver services in the patient's own home this means that the patient's home is the CCG employee's place of work. The CCG should be mindful of the need to balance its duties to the patient with the duty to provide the member of staff with a reasonably safe place of work.

13.4 Problems can arise if the CCG uses staff to deliver care in a patient's own home. The patient's home is the staff's place of work and the CCG therefore has a duty to deliver a reasonably safe place of work for its staff. The duties to staff are not defined by the best interest of the patient but exist independently of such obligations. There are a series of issues that CCG managers should consider:

a) **The interests and rights of other occupants of the home**: A CHC package can only be delivered to a patient in their own home if the legal owners of the home agree to staff coming into the home to deliver care. Where the patient is not the legal owner of the property, clear agreement is needed from the property owner to enable care to be delivered. The CCG should ensure that it is not left in the position where care staff do not have unimpeded access to the property;

b) **Health and Safety issues:** The CCG must consider whether the patient's home is a reasonably safe environment for staff to work in. Whilst some allowance can be made for the fact that the home environment does not need to be maintained to the same standard as a hospital, a risk assessment should be carried out and action taken to avoid any very obvious risks. The patient's home needs to be a reasonably safe place of work for that particular member of staff. So if, for example, a member of staff is allergic to dog hair and the patient has a dog, it would be unreasonable to expect that member of staff to work in the patient's home even if would be fine for others.

c) **Harassment Issues:** Predictable and/or repeated harassment from the patient, members of the patient's family or visitors could leave the CCG or a domiciliary care provider in breach of its duty to its own staff. Whilst some allowance must be made to permit the patient to live life in their own way, verbal or physical abuse, racially or sexually improper comments or any other action which is designed or likely to impede staff in their ability to deliver care must be addressed by the CCG. In extreme cases, this can arise where members of the patient's family (who may be expert in managing the patient's medical condition) are so insistent on their own ways of doing things and/or can be so directing that they impede the ability of staff to do their job. These problems require balancing duties to staff with duties to patients. If CCG staff are aware of these types of problems they should report them and seek advice and support without delay.

13.5 Whilst CCG decision makers obviously wish to do the best for individual patients, they should also bear in mind that the CCG has a statutory duty under the NHS Act to break even financially. This means that the services that the CCG is able to provide under section 3 are inevitably subject to a degree or rationing or prioritisation (as is the case with all NHS provided health services and indeed virtually all health services across the world). Thus if the CCG has reached the point where it would be able to provide an appropriate package of care for a patient in a care home at a significantly lower cost, CCG staff should look very carefully to decide whether it is justifiable under their own policies to pay a higher sum to the maintain the patient in his or her own home. This is an area where specialist legal advice is often sought.

The extent of services (other than accommodation) that are required to be provided as part of the CHC package.

13.6 Patients often require a wide range of nursing and other services as part of a package of CHC. Whilst this needs to be considered on a case by case basis, CCGs should be mindful that they have a duty to act fairly between different classes of patients and

there are many patients whose healthcare needs cannot be fulfilled by the NHS, either in part or in whole. An assessment may, for example, indicate that a patient has a need for 10 hours nursing support a week. That assessment does not lead to a statutory duty to provide 10 hours support a week. The CCG has a statutory duty to break even financially each year and is entitled to apply its policies fairly and to provide a package of support which is consistent with the level of support provided to other patients[53]. That may, in the above example, mean that the CCG is only able to offer 5 hours nursing support a week. Provided the CCG has followed its own procedures it is highly unlikely that such a decision could be challenged in the courts. As Mr. Justice Ousley said in *T & Ors, R (on the application of) v London Borough of Haringey*[54]:

> "If [*the CCG*] is providing the resources, it is entitled to decide how they should be used"

13.7 CCGs should have policies to assist officers making decisions about what level of support should be provided to patients who qualify for CHC. In reaching these decisions it is entirely proper and probably inevitable that the CCG will take into account the cost of services. The courts have consistently upheld the right of NHS bodies to ration services for patients so that the CCG can make a rational and fair allocation of services to the wide range of people that it needs to serve out of its limited budget.

14 Support for patients who do not qualify for CHC or NHS funded care.

14.1 If a patient does not qualify for CHC, the NHS is under no obligation to meet all or any part of the accommodation or social care costs of a patient who is not in hospital. However, the CCG may still be responsible for providing a broad range of healthcare services to the patient, including offering to provide primary care services from a GP

[53] See the observations of Mr. Justice Ouseley in T & Ors, R (on the application of) v London Borough of Haringey [2005] EWHC 2235 (Admin).
[54] See footnote 13.

practice. Thus, the CCG is obliged to consider how much of the healthcare needs it is able to meet, including meeting nursing needs and to balance those needs against the other demands on its budget.

14.2 The Guidance states that, for patients who do not qualify for CHC includes the following:

> "The range of services which the NHS is expected to arrange and fund includes but is not limited to:
>
> - Primary health care
> - Assessment involving doctors and registered nurses
> - Rehabilitation and recovery (where this forms part of an overall package of NHS care as distinct from intermediate care)
> - Respite health care
> - Community health services
> - Specialist health care support
> - Palliative care"

14.3 If a patient does not qualify for CHC, the local authority may have a responsibility for providing such social care, including personal care, to the patient (depending on the patient's circumstances and the local authority's policies). The local authority cannot be expected to provide specialist NHS care (either in quantity or quality). However, if the CCG has properly followed the 2012 Regulations as set out above, the issue as to whether the patient needs specialist care which is beyond that able to be provided by a local authority will already have been considered as part of the CHC process. Hence, as long as the process is followed correctly, by the time the CCG has got to the point of deciding that a patient does not qualify for CHC, the overall level of social care needed by the patient should not be beyond that which a local authority is entitled to provide. The range of social care and personal support services to be provided by the local authority will be determined by the local authority applying their own policies. This may well not meet all the social and personal care needs of the patient but that decision does not impose any duty on the CCG to plug the gaps.

14.4 There may, of course, be elements in the overall care package which comes out of the care planning process which need to be provided by a doctor or nurse or other NHS specialist. Those elements, if they are to be provided (and the CCG does not of course need to meet every healthcare need), will have to be provided by CCG staff or otherwise funded by the CCG. The core accommodation and social care costs however should not be met by the CCG.

15 **Cost sharing arrangements with local authorities outside CHC.**

15.1 There is a widespread practice or dividing up the costs of meeting services for patients outside hospital who have significant health needs but do not qualify for CHC between the NHS and local authorities, often on a 50/50 basis. The National Framework Guidance states at paragraph 108:

> "It is the responsibility of the CCG to plan strategically, specify outcomes and procure services, to manage demand and provider performance for …. the healthcare part of a joint care package"

15.2 Thus where a patient is not eligible for CHC, the responsibility on the CCG is to fund the "healthcare part" of a joint care package. However the costs of accommodation and social care services for patients who are not eligible for CHC should generally not be paid by an NHS commissioning body. That Guidance accurately identifies that, where a patient is not eligible for CHC, CCGs should only fund the "healthcare part of a joint care package". That means the cost of services of those healthcare professionals who are needed to provide support to a community based patient. This duty is made clear at paragraph 114 of the National Framework which provides:

> "There will be some individuals who, although they are not entitled to NHS continuing healthcare (because 'taken as a whole' their needs are not beyond the powers of a local authority to meet), but nonetheless have some specific needs identified through the Decision Support Tool that are not of a nature that an LA can solely meet or are beyond the powers of an LA to solely meet. CCGs should work in partnership with

their LA colleagues to agree their respective responsibilities in a joint package of care, including which party will take the lead commissioning role"

15.3 The Practice Guidance also addresses some of the problems associated with such arrangements[55]. It provides:

"PG 58 What are joint packages of care?

58.1 Where an individual's care/support package is supported by both the NHS and the LA this is known as a 'joint package of care'. The Framework advises that if an individual does not qualify for fully funded NHS continuing healthcare the NHS may still have a responsibility to contribute to meeting that individual's healthcare needs. The respective powers and responsibilities of each organisation should be identified by considering the needs of the individual. Where there are overlapping powers and responsibilities, a flexible, partnership-based approach should be adopted based on the most appropriate organisation to meet the specific need.

58.2 Although the LA can provide some healthcare services (within legal limitations of LA social care powers) the assessment and DST may have identified some healthcare needs that are not of a nature that the LA could solely meet, or that are beyond the powers of the LA to solely meet, and therefore these may be the responsibility of the NHS to provide. Practitioners should draw on their knowledge and skills regarding the assessed needs and their organisation's powers to meet them, and work together to agree respective responsibilities for care provision in a joint package of care.

58.3 In a joint package of care the CCG and the LA can each contribute to the package by:

a) delivering direct services to the individual

b) commissioning care/services to support the care package, or

c) transferring funding between their respective organisations (where the needs are ones that the NHS and the LA both have the power to meet).

[55] See pages 89/90 of the National Framework.

58.4 Although the funding for a joint package comes from more than one source it is quite possible that one provider, or the same worker(s), could provide all the support. Joint care packages can be provided in any setting. Examples can include:

- someone in their own home with a package of support who does not have a primary health need but has a package of support comprising both health and social care elements
- someone in a care home with nursing who has nursing or other health needs that, whilst not constituting a primary health need, are clearly above the level of needs intended to be covered by NHS-funded nursing care
- someone in a care home (without nursing) who, although not eligible for NHS continuing healthcare, has some specific health needs beyond the power of the LA to meet, requiring skilled intervention or support where these needs cannot practically be met by community nursing services.

58.5 Joint/coordinated CCG and LA reviews should be considered for any joint package in order to maximise effective care and support for the individual"

15.4 The importance of the NHS only funding "healthcare costs" of a joint package is also emphasised in PG 61 which provides

"PG 61 In a joint package does the DST define which elements are the responsibility of the NHS and which are the responsibility of social services?

61.1 No. The completed DST will help to indicate the nature and levels of need of an individual, but it does not attribute responsibility for individual elements of a care package. Where a person is not entitled to full NHS continuing healthcare the cost of a jointly funded support package are a matter of negotiation between the CCG and the local authority based on the assessed needs of the person and the limits of what a local authority can fund.

61.2 One approach to identifying respective funding responsibilities is to analyse a 24 hour/48 diary of the tasks and interventions required to meet the individual's needs in order to identify which elements are beyond local authority powers, which are areas where both health and social care have power to provide, and which areas which are clearly social care responsibility.

61.3 CCGs and local authorities should agree protocols for dealing with jointly funded packages/placements. Local dispute resolution processes should cover both disputes over joint funding as well as NHS continuing healthcare eligibility"

15.5 However, the duty to fund services to meet "specific needs" will not generally (if ever) extend to a duty to contribute to the costs of accommodation or social care services for such a patient. Outside CHC arrangements it would generally be beyond the powers of the CCG[56] to expend monies to support social and personal care services because they are likely to be outside the range of services that the CCG has a statutory power to deliver under section 3 of the National Health Service Act 2006.

15.6 The scope and limits on the duties of the NHS to provide accommodation as part of its overall responsibilities are not always fully understood. The correct position was set out by HHJ Hickinbottom (now Hickinbottom LJ) in *Secretary of State for Work and Pensions v Vale and others* (CDLA/3161/2003 dated 27 July 2005) where the Judge said:

"Perhaps because it appears not to be mentioned in circulars issued by the Department of Health, it seems often to be overlooked that, where a person requires accommodation because of his or her need for nursing services (rather than because of a need for "care and attention" to which any nursing services required are merely incidental or ancillary), it is the duty of the National Health Service to make such accommodation available under section 3 of the 1977 Act, either directly or by making arrangements under section 23 to place a person in a nursing home. That is because the implication of *Coughlan, White* and *Botchett* is that the accommodation that is required in those circumstances falls within the scope of section 3(1)(a) or (b) of the 1977 Act. A local authority has no power to provide such accommodation due to the effect of section 21(8) of the 1948 Act. Of course, a person who is entitled to services may choose not to take advantage of the National Health Service and instead to pay for his accommodation and nursing from his own resources or with help from a relative or friend. However, that must be a matter of choice, exercised by someone competent to make the relevant decision.

[56] The CCG's powers are limited by statute and it would be ultra vires for the CCG to act beyond these powers.

This is probably still good law despite the Court of Appeal's decision in *Whapples* (see paragraph 3.2 above) but legal advice should be sought if needed.

15.7 Thus if the CCG enters into a 50/50 cost sharing arrangement for a patient who does not qualify for CHC, the CCG may well be contributing to the cost of the patient's accommodation in circumstances where the CCG has not power to meet any part of the patient's accommodation costs. The better approach is for the CCG to work out the (approximate) cost of the healthcare inputs into the package which the CCG is prepared to fund, and then to make a contribution to the overall package which is consistent with the level of its commitment. If there are disputes about the right division of costs between the local authority and the CCG this can be resolved using the dispute resolution process set out above.

16 **Subsequent review of CHC decisions for eligible patients.**

16.1 When a decision is made that a patient is eligible for CHC, the panel should fix a date for reviewing that decision. The initial review should be after 3 months and then the review should happen at least annually. However if a patient's medical condition is expected to change (for the better or worse) within the year a review after less than a year may well be appropriate.

17 **Special categories of patients**

17.1 There are some categories of patients whose special needs stand apart from the CHC process or who require special consideration. These include:

a) Children;
b) Palliative or near death care for patients who are in a terminal phase of life;
c) Patients with learning difficulties;
d) Former long stay patients;
e) Patients where there are section 28A agreements; and

f) Patients leaving in-patient mental health care under section 117 of the Mental Health Act 1983.

17.2 **Children:** The National Framework for CHC only applies to adults. The National Framework for Children and Young People's Continuing Care[57] provides a framework for making decisions relating to children. The scheme is somewhat different to CHC for adults for a variety of reasons, including the need for educational input for the child, the impact of special educational needs and the fact that the child will almost certainly be a "*child in need*" under section 17 of the Children Act 1989 and thus the duties on the local authority will be different to the local authority's duties to an adult who needs services under the Care Act 2014. Hence, no assumption can be made that the legal framework set out above applies in the case of children.

17.3 **Palliative or near death care for patients who are in a terminal phase of life:** CHC has always been awarded on a more generous basis to patients who are in the final few months or weeks of their lives. Such patients should be assessed using the Fast Track Tool as described above. However those patients who do not fulfil all of the strict criteria to come within the Fast Track Tool have generally found a substantially more generous approach is afforded to the allocation of support in their cases.

17.4 **Patients with learning disabilities:** There are no special rules for patients with learning disabilities in relation to CHC, although the inclusion of "*challenging behaviour*" as one of the domains in the Decision Support Tool which can lead to a "priority need" can often lead to such patients being treated in a separate way to other groups of patients.

17.5 The recognition that the vast majority of learning difficulty patients have a primary need for social care support rather than having a primary healthcare need has led to

[57] See https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework

the transfer of responsibility for this group of patients from the NHS to community care over the last 30 years. However, there remain large numbers of learning disabled patients who continue to be funded by the NHS solely because they are assessed as having a high level of challenging behaviour. The Decision Support Tool indicates that patients with the highest level of challenging behaviour can qualify for CHC on this ground alone, provided the level of severity is at the very highest end of the spectrum. However even with such patients, the test under the 2012 Regulations is whether the highest level of challenging behaviour gives rise to a primary health need. If the challenging behaviour gives rise to hugely complex social care management without the direct input on a regular basis of healthcare professionals, the primary health need test is unlikely to be satisfied even if the Decision Support Tool points towards CHC eligibility. The issues are accurately summarised at PG38[58] which provides:

> **"PG 38 How does the Decision Support Tool (DST) and primary health need eligibility test apply to people with learning disabilities?**
>
> 38.1 The DST should be used for all adults who require assessment for NHS continuing healthcare, irrespective of their client group/diagnosis. The tool focuses on the individual's needs, not on their diagnosis. Directions require that the DST is used to inform the decision as to whether someone has a primary health need, and if they do they must be deemed eligible for NHS continuing healthcare.
>
> 38.2 In all cases eligibility for NHS continuing healthcare should be informed by good quality multi-disciplinary assessment. Where the individual has a learning disability it will be important to involve professionals with expertise in learning disability in the assessment process as well as those with expertise in NHS continuing healthcare. It will also be important to ensure that the assessment process is person-centred and that family members/carers are fully and appropriately involved.
>
> 38.3 Standing Rules set out the meaning of 'Primary Health Need' in relation to the limits of local authority responsibility and paragraph 33 of this Framework explains the primary health need test in some detail. It is important to understand that this test is about the balance of needs once all needs have been mapped onto the DST.

[58] See page 80 of the National Framework.

38.4 This Framework makes it clear (see paragraph 58) that "the reasons given for a decision on eligibility should not be based on....the use or not of NHS employed staff to provide care; the need for/presence of "specialist staff" in care delivery or any other input related (rather than needs-related) rationale."

38.5 The question is not whether learning disability is a health need, but rather whether the individual concerned, whatever client group he or she may come from, has a 'primary health need'.

38.6 The indicative NHS continuing healthcare eligibility threshold levels of need as set out in the user notes apply equally to all individuals irrespective of their condition or diagnosis.

38.7 Previous or current pooled budget, joint funding, Section 75 agreements or legacy funding arrangements and the funding transfer to local authorities in April 2009 do not alter the underlying principles of NHS continuing healthcare entitlement.

38.8 The Department of Health made it clear that the funding transfer to local authorities in 2009 was for social care and did not include those eligible for NHS continuing healthcare36. However this Framework points out that some historic local agreements relating to particular groups of clients with learning disabilities (for example following hospital/campus closures) can mean that these individuals are not required to be considered separately for NHS continuing healthcare.

38.9 It is crucial that the detail of these local agreements are examined in order to clarify whether or not the Framework applies. It is important to ensure that all adults are treated equitably under the Framework.

38.10 Some people have concerns about the potential loss of personalisation/control for people with learning disabilities (and other client groups) if their care is commissioned/provided/funded by the NHS. However, CCGs have considerable existing legal powers to maximise choice and control, including the provision of 'personal health budgets'. The Government has announced that from April 2014, anyone in receipt of NHS continuing healthcare will have the right to ask for a personal health budget, including a 'direct payment'.

38.11 Whatever the outcome of the eligibility decision regarding NHS continuing healthcare, commissioning should be person-centred and needs-led. NHS commissioners for people with learning disabilities should be familiar with and apply

the principles of 'Valuing People' and 'Valuing People Now'. For further information on commissioning and care planning please see paragraphs 108 - 111 of this Framework. This is an area where local authorities and CCGs need to work closely in partnership to ensure the best outcome for the individuals concerned, whether or not the care package is to be fully funded by the NHS.

38.12 Where an individual is eligible for NHS continuing healthcare, CCGs have responsibility to ensure that effective case management is commissioned. Consideration should be given as to who is best placed to provide this function, and clear responsibilities agreed. Amongst other options it may be appropriate to secure this from the local authority who may have previous knowledge of the individual concerned or have staff with particular skills and experience to undertake this function on behalf of the CCG. Please see PG80 below regarding responsibilities for case management"

17.6 Whilst cases are, of course, fact specific, a number of CCGs have undertaken review processes of patients who have been awarded CHC on the basis of challenging behaviour alone in order to determine whether this genuinely leads to a primary health need.

17.7 **Former long stay patients:** There are a limited group of former residents of long stay mental hospitals where the NHS has been provided with dowry funding to support the patient for the rest of their lives. If a patient falls into this category then, if they do not qualify for CHC under the National Framework and are being supported by local authority provided social care, the money provided under the dowry should be passported through to the local authority under "section 28A" agreements – now agreements under section 256 of the National Health Service Act 2006. However these are payments by CCGs to support the discharge by local authority social services departments of social services functions – i.e. the provision of community care services by social services authorities and not services for which the CCG has statutory responsibility.

17.8 Otherwise, there are no special rules for former long stay patients. Over the years this group of patients have been supported by the NHS, by the benefits system and

are now, where appropriate, supported by local authorities. Large sums of government funding have been passed from one department to another as responsibility has moved. The fact that a patient, who does not have a dowry payment, was once supported in an NHS facility does not create a responsibility on the NHS to meet the costs of that patient for the rest of his or her life. However there may well be circumstances where the NHS chooses to provide some support for such patients even though under no legal obligation to do so. The details of such support are outside the scope of this chapter.

17.9 **Patients where there are agreements with local authorities:** There are some patients or groups of patients where the NHS has entered into long term agreements with local authorities for support to be provided by local authorities to these patients. These agreements can take one of 2 forms, namely:

a) Section 75 agreements in which local authorities agreed to provide specified health care services on behalf the CCG; or

b) Section 256 agreements under which the CCG provides resources to a local authority to enhance the delivery of local authority social care services so as to reduce the demand for healthcare services.

17.10 There may well be CHC patients who can benefit from local authority services provided under either type of agreement. However, the existence of such a service arrangement should not affect a patient's eligibility for CHC. It may however affect the identity of service provider who delivers services under a package for a CHC eligible patient.

17.11 Guidance on this is provided by PG 95 which states:

> **"PG 95Can a local authority act as a 3rd party to administer direct payments to someone who has been deemed eligible for NHS Continuing Healthcare?**

95.1 Where a CCG has been authorised to have powers to make NHS Direct Payments, they can reach a formal agreement (under Section 75 of the NHS Act 2006) to transfer these powers (and funding) to the relevant local authority. This would enable the local authority to make direct payments to individuals receiving NHS continuing healthcare.

95.2 Where an individual is not entitled to NHS continuing healthcare but is receiving a joint package of care between the LA and CCG, they can reach agreement for the local authority to make a direct payment for the elements of the care package that are within local authority powers. The remaining elements of the care package (beyond local authority powers) should be arranged by the CCG in a manner that, as far as possible, is compatible with the direct payment arrangements.

95.3 Where the CCG has not been given powers to offer direct payments, there is currently 14 no provision to allow a local authority to make direct payments for NHS continuing healthcare on their behalf. However, the CCG should always consider the other models of personal health budget that are available for all CCGs to use, including a) notional personal health budget held by the CCG and used in partnership with the individual; and b) a real personal health budget held by a 3rd party such as a brokerage organisation, who should agree with the individual how it is to be spent.

95.4 CCGs should commission services using models that maximise personalisation and individual control and that reflect the individual's preferences, as far as possible. It is particularly important that this approach should be taken when an individual who was previously in receipt of an LA direct payment begins to receive NHS continuing healthcare; otherwise they may experience a loss of the control they had previously exercised over their care"

Thus, in the right case, these arrangements may well assist an individual patient.

17.12 **Patients leaving mental health care – section 117 of the Mental Health Act 1983:** Patients who are leaving detention under the Mental Health Act 1983 have a legal right under section 117 of the 1983 Act to after care services. This is entirely separate from CHC funding. Section 117 sets up a legal duty which is owed to relevant patients jointly by a CCG and the relevant local authority. Such patients are entitled to a package of support arising from their mental health needs without the

need to be assessed under the CHC regime. This is explained in PG64 and PG65[59] which provide:

> **"PG 64 What is the relationship between NHS continuing healthcare and section 117 after-care under the Mental Health Act?**
>
> 64.1 Services for needs that fall to be met as after-care services under section 117 of the Mental Health Act 1983 should be provided under that legislation rather than as NHS continuing healthcare. Only needs that are not section117 after-care needs should be considered for NHS continuing healthcare eligibility in the usual way. For example, the individual might have or develop physical health needs which are distinct from the section 117 needs, and which separately constitute a primary health need. There should be no charge to the individual for section 117 services, regardless of whether they are being funded by a CCG or an LA.
>
> 64.2 LAs and CCGs should have agreements in place detailing how they will carry out their section 117 responsibilities, and these agreements should clarify which services fall under section 117 and which authority should fund them. LAs and CCGs may use a variety of different models and tools as a basis for working out how section 117 funding costs should be apportioned. However, where this results in a CCG fully funding a section 117 package this does not constitute NHS continuing healthcare.
> 64.3 It is preferable for the CCG to have separate budgets for funding section 117 and NHS continuing healthcare. Where they are funded from the same budget they still continue to be distinct and separate entitlements
>
> **PG 65 Is there any additional guidance on the relationship between NHS continuing healthcare and the Mental Health Act 1983?**
>
> 65.1 Arrangements under the Mental Health Act are separate and different from NHS Continuing Healthcare and the two should not be confused. The above guidance particularly deals with Section 117, however the same principle (regarding the need to determine whether the services are provided under the Mental Health Act or under NHS continuing healthcare) applies where an individual is subject to Section 17 leave or to a Section17A Supervised Community Treatment Order"

17.13 It is possible for patients to have both profound physical and mental health needs. In that case, a patient would fall to be assessed for their physical needs under the CHC

[59] See page 93 of the National Guidance.

system and would be entitled to support under section 117. Aside from such unusual circumstances, patients being discharged from compulsory in-patient mental health should not be assessed for CHC. The division of responsibility between health and social services should be set out in a local agreement and this is a rare occasion on which CCGs can agree to meet 50% of the costs of a care package.