Landmark Chambers Guide to NHS Continuing Healthcare and NHS-funded nursing care for adults in England¹

Part A: Introduction.

What is NHS Continuing Healthcare?

- 1. This is a general guide to the law and practice around NHS Continuing Healthcare ("CHC") for adults. CHC is the name given to a package of care for an adult that is arranged and funded solely by an NHS body as services under the National Health Service Act 2006 ("NHSA 2006") for adults² 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'. The Department of Health and Social Care ("DHSC") has published a summary about CHC in the form of a leaflet NHS Continuing Healthcare and NHS-funded nursing care: public information leaflet (amended 2022)³. Patients who are eligible for CHC should receive a package of NHS funded health and social care services and thus should not need to rely on social care services provided by a local authority under the Care Act 2014 (which are means tested).
- 2. The core legal documents governing the CHC eligibility tests are in Part 6 of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 ("RSR Regs")⁴. Details about the services that an eligible patient should receive are set out in the Guidance document titled the 'National Framework for NHS Continuing

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² An adult is a person over the age of 18. Equivalent services for children are considered under a different framework which is described in chapter 17.

³ https://www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet/public-information-leaflet-nhs-continuing-healthcare-and-nhs-funded-nursing-care--2

⁴ SI No 2996. These Regs have been amended on many occasions since they were made and thus, if possible, readers should use LexisNexis or Westlaw to make sure they are referencing an up-to-date version. The version referred to in this chapter dates from 1 March 2024.

Healthcare and NHS-funded Nursing Care' ("the National Framework")⁵ published by the DHSC. The text of the National Framework referred to in this Guide dates from July 2022.

3. The present version of the National Framework defines CHC as follows:

"NHS Continuing Healthcare (CHC) means a package of ongoing care that is arranged and funded solely by the National Health Service (NHS) where the individual has been assessed and found to have a 'primary health need' as set out in this National Framework. Such care is provided to an individual aged 18 or over, to meet health and associated social care 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 is not determined by the setting in which the package of support can be offered or by the type of service delivery"

4. In terms of the key concept of a 'primary health need', the National Framework states:

"An individual has a primary health need if, having taken account of all their needs (following completion of the Decision Support Tool), 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. Having a primary health need is not about the reason why an individual requires care or support, nor is it based on their diagnosis; it is about the level and type of their overall actual day-to-day care needs taken in their totality"

5. CHC is thus a package of health and social care services (and the provision of 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 NHS⁶. This is shown in the *National Framework*, which provides:⁷

⁵ See https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf

⁶ In practice almost invariably by the ICB which has commissioning responsibility for the person.

⁷ At para 55.

"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"

6. 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 Integrated Care Boards ("ICBs") contract with private care homes to provide the required services (as they are permitted to do under section 12ZA of the National Health Service Act (NHS Act) 2006). The care home fees thus become costs that are required to be met by the local ICB.

Part B: A history of government policy concerning NHS CHC. Background

7. The present way in which CHC works can only be understood properly by taking account of the history of the attempts by the NHS to define who should receive a wholly NHS funded package of care outside of a hospital setting. The concept of CHC 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 without 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 thus for those with means charges fall to be paid.

- 8. When the NHS was created in 1948, 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. The NHS also supported patients with learning difficulties who mainly needed social care in larger mental health hospitals. Patients with long-term conditions were also 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. 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').
- 9. There are two 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. Second, 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.
- 10. Hence, one effect of changing medical patterns of care which moved medical treatment for patients with complex conditions out of the hospital environment

⁸ 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.

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 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. However, 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.

National Health Service and Community Care Act 1990 and the DH guidance

11. 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 ("NHSCCA 1990") came into force in April 2003. The NHSCCA 1990 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 NHSCCA 1990 was accompanied by a guideline document, HSG(92)50, issued by the NHS Management Executive⁹ 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"

12. 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

⁹ The NHS Management Executive was part of the Department of Health.

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"

- 13. 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 duty or only a power 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.
- 14. 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.
- 15. 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.
- 16. The DHSC¹⁰ issued supplementary guidance in February 1996, which referred to the danger of these eligibility criteria being interpreted in an over-restrictive way. 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.

The Coughlan case.

17. 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 p Coughlan*.¹¹ 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, and thus the Health Authority acted unlawfully in seeking to pass responsibility for the care home to the local authority. The Judge said the provision of both general and specialist nursing services were 'health care' and could not

¹⁰ Known as the Department of Health at the time.

¹¹ [2001] QB 213, (1999) 2 CCLR 285.

classified as 'social care'. His view was that the health authority was wrong in law because:

- ".. both general and specialist nursing care remain the sole responsibility of the health authorities"
- 18. 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 (at para 30) are worth setting out in full as follows:
 - "(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"
- 19. 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 RSR Regs. 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.

Section 49 of the Health and Social Care Act 2001

- 20. The next significant step was section 49 of the Health and Social Care Act 2001 ("HSCA 2001") 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 state-funded personal care for elderly people in need should be made available to everyone. It 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 HSCA 2001.
- 21. The broad effect of section 49 of the HSCA 2001 (with the relevant provisions now being in s22 of the Care Act 2014¹² ("CA 2014")) was 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.

The 2001 Continuing Care guidance.

22. Following the *Coughlan* judgment, the DHSC released some fairly opaque and possibly unhelpful guidance, "*Continuing Care: NHS and local council's responsibilities* (HSC 2001/015)".¹³ This guidance introduced a distinction between 'continuing care' and 'Continuing NHS healthcare' for the first time. It defined continuing care as follows:

¹² See para XX below for a detailed examination of the effect of S22 CA 2014.

^{13 500}

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

'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"

23. In contrast, the guidance defined 'Continuing NHS Healthcare' as follows:

'Continuing NHS healthcare' 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"

- 24. The guidance then recommended that local health authorities should set their own eligibility criteria to determine which patients were and were not entitled to Continuing NHS healthcare (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:
 - 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 judgment).
 - 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.
 - 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"

- 25. This guidance demonstrated the tensions in government which have always been present in CHC policy. There are two 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.
- 26. Second, there are tensions between patients (and their families) and the NHS. Patients naturally want to fall under NHS CHC 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 on to the next generation is thwarted. While 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/local authority tension and the NHS/patient and family tension run through CHC policy like the word "Brighton" runs through a stick of seaside rock. They are always present, albeit often just below the surface.

27. In 2003, the Parliamentary and Health Service Ombudsman ("**PHSO**") issued a special report, *NHS funding for long term care*, ¹⁴ 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 PHSO reported on the DHSC's 2001 *Continuing Care* 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:

¹⁴ February 2003, HC 399. Available here:

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).

- 28. Given the legal framework within which the NHS was then operating, two significant and legitimate criticisms can be made of the 2003 PHSO report. First, it criticised variations between the polices adopted by different health authorities. That was an understandable policy criticism but, as a matter of law, it was 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 15. Second, 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.
- 29. The 2001 guidance was also subsequently the subject of some pointed criticism by Charles J in *R (Grogan) v Bexley NHS Care Trust and others*. ¹⁶ However, the judge in that case importantly noted: ¹⁷
 - ". . . 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'.

30. The Judge also said:18

¹⁵ The right of different NHS bodies to have different approaches was approved in *Coughlan* and a series of further cases including Bean J in *R (Rogers) v Swindon NHS Primary Care Trust & Anor* [2006] EWHC 171 (Admin) who said at para 70 regarding inconsistent policies on the use of a cancer drug "*Which is the better policy is a matter for political debate, but it is not an issue for a judge. The question for me is whether Swindon's policy is irrational and thus unlawful".*

¹⁶[2006] EWHC 44 (Admin), (2006) 9 CCLR 188.

¹⁷At para 37.

¹⁸At para 39.

"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"

31. Charles J observed that the 2001 DHSC 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 was not a party 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.

Primary care trusts and strategic health authorities

- 32. 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 'postcode 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 DHSC to require CHC eligibility criteria to be set by 'Strategic Health Authorities' ("SHAs") from 1 April 2004.
- 33. PCTs remained the statutory decision-makers to decide which patients were eligible for CHC but, after 1 April 2004, PCTs were required to use the SHA eligibility criteria to determine eligibility for NHS CHC. This change was aimed at delivering a greater level of consistent approach over the area of the SHA. At this stage, there were ten (later nine) SHAs covering the whole of England. However, there were still elements of postcode 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.

34. The 2001 guidance introduced a further stage for patients, namely the SHA Review Panel¹⁹. These panels were commonly referred to as 'appeal panels' but they were not final decision-makers. The panels reviewed cases and made 'recommendations' to the PCTs, but could not take their own decisions. However, few if any of the recommendations were not accepted by PCTs.

The publication in 2007 of a National Framework for CHC and NHS Funded Nursing Care.

35. The adoption of SHA eligibility criteria and SHA appeal panels improved consistency but did not lead to a completely uniform approach across the country, and hence complaints based on variations between areas continued. The government responded by introducing national CHC criteria covering the whole of England. These were set out in the first *National Framework for NHS Continuing Healthcare*, which was published in October 2007 ("the National Framework"). The National Framework was updated in 2009 and a further edition was published in 2012. That edition was supplemented by a Practice Guidance document published by the DHSC. A new version of the National Framework was then published in 2018, along with a slightly amended Practice Guidance document. Those two documents were then brought together in a single document. The current National Framework (including Practice Guidance) at date of writing, namely 1 March 2024, is dated 1 July 2022²⁰.

Part C: Decision making to determine who is eligible for CHC.

- 36. In any case related to CHC there are, almost inevitably, two separate questions namely:
 - (a) Is the patient entitled to CHC (or Funded Nursing Care); and
 - (b) If the patient is entitled to CHC, what package of care is the patient entitled to receive from the ICB consequent upon his or her eligibility.

¹⁹ These panels now operate as NHS England appointed Independent Review Panels.

²⁰ See https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

37. A large part of the legal framework set out below guides ICBs when making eligibility decisions. However, in practice, working out whether the ICB is properly discharging its obligations to an eligible patient can be equally challenging. The balance of this Guide is thus divided into two sections, namely (a) a guide to the law on eligibility decisions and (b) a guide to the law about care planning and the delivery of care packages.

The rules for determining whether a person is eligible for CHC.

- 38. The present position is that a person's eligibility for CHC is determined by an ICB. Each ICB is required to apply mandatory rules in part 6 of the RSR Regs.²¹ These rules follow the decision-making process set out in 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 (almost always) the relevant ICB.
- 39. The National Framework is effectively split into two parts. The main part (i.e. pages 1 to 108) contains guidance on the principles and processes of CHC. Pages 109ff contain a section called 'Practice Guidance'²², which consists of a series of questions and answers. 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 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 as a whole in order to seek to draw out a consistent meaning. The proper interpretation of guidance is for the courts, not for an ICB or even NHS England.²³

The legal basis for the provision of NHS CHC

²¹SI No 2996.

²²Starting at page 109.

²³See Tesco Stores Ltd v Dundee City Council (Scotland) [2012] UKSC 13.

- 40. Section 3 of the NHSA 2006 requires ICBs to make arrangements to provide the following services:
 - "(1) An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility—
 - (a) hospital accommodation,
 - (b) other accommodation for the purpose of any service provided under this Act,
 - (c) medical services other than primary medical services (for primary medical services, see Part 4),
 - (d) dental services other than primary dental services (for primary dental services, see Part 5),
 - (e) ophthalmic services other than primary ophthalmic services (for primary ophthalmic services, see Part 6),
 - (f) nursing and ambulance services,
 - (g) such other services or facilities for the care of pregnant women, women who are breastfeeding and young children as the board considers are appropriate as part of the health service,
 - (h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service,
 - (i) such other services or 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 board considers are appropriate as part of the health service, and
 - (j) such other services or facilities as are required for the diagnosis and treatment of illness"
- 41. CHC involves the provision of a 'package' of care and support services to 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)(d)(e) and (f) (for medical and nursing services), section 3(1)(b) (for accommodation), section 3(h) if palliative care is required and section 3(1)(i) (for social care and other services). In *R* (*Whapples*) *v Birmingham*

Cross City Clinical Commissioning Group and another,²⁴ the Court of Appeal accepted that the power to create the *National Framework* was contained in section 2 of the NHSA 2006.

- 42. 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 2006. That raises the slightly difficult question as the meaning of the term 'hospital' in the NHS Act 2006.
- 43. The word 'hospital' is widely defined in section 275 of the NHS Act 2006 to include 'any institution for the reception and treatment of persons suffering from illness' and 'any institution for the reception and treatment of persons during convalescence or persons requiring medical rehabilitation'. 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 Learnington Spa*; ²⁵ Chief Adjudication Officer v White; ²⁶ and Botchett v Chief Adjudication Officer. ²⁷ See also R (DLA 2/06) which explains the legislative history in some detail.
- 44. 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.²⁸

²⁴[2015] EWCA Civ 435, (2015) 18 CCLR 300.

²⁵[1954] Ch 530.

²⁶Reported as R(IS) 18/94.

²⁷Reported as R(IS) 10/96.

²⁸ At para 32

- 45. 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.
- 46. The extent of the NHS's obligation to provide 'other services' under section 3(1)(i) is subject to the additional qualification that they are only such services as the ICB considers to be 'appropriate as part of the health service'. That clearly gives the ICB 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 ICB must follow the guidelines set out in the *National Framework* unless it has a good reason to depart from the guidance.
- 47. In a limited number of cases, NHS England may be the body with commissioning responsibility for a patient's CHC, for example for individuals who are prisoners or serving military personnel and their families.²⁹ In general, however, this Guide will refer to the ICB decision-making process, although where NHS England has commissioning responsibilities, the National Framework applies to it equally.³⁰ Its other duties in relation to CHC are explored below.

The statutory decision-making process which ICBs have to follow to determine who is eligible for CHC?

Overview

48. From 1 October 2007, the *National Framework* guidance was required to be used by local NHS decision-makers to determine eligibility. Following the demise of PCTs in April 2013, the rules on CHC eligibility are now contained in Part 6 of the RSR Regs. These Regulations set out a statutory decision-making process which each ICB is required to follow to determine whether a patient is eligible for CHC.

²⁹ Please see Chapter 4 for a full discussion of NHS England's commissioning responsibilities and Chapter 9 for an explanation as to how commissioning responsibilities are divided between NHS England and ICBs.

 $^{^{30}}$ See the definition of 'relevant body' in regulation 2 of the RSR Regs 2012.

- Regulation 21(12) provides that 'In carrying out its duties under this regulation, a 49. relevant body³¹ must have regard to the National Framework". Regulation 20(1) provides that "National Framework" means the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care issued by the Secretary of State and dated 30th May 2022'32. This means that an ICB, when making decisions about CHC, must take into account that version of the National Framework. As made clear in Whapples, 'the National Framework does not amount to a direction' and its interpretation is 'ultimately a matter for the court having regard to its development, statutory context and purpose.' An ICB is thus obliged to take the National Framework into its account when making decisions about CHC, but its decision making must follow the framework in Reg 21. If there is any conflict between the National Framework and the RSR Regs, the RSR Regs must take precedence. In principle, an ICB that took a decision that departed from the National Framework may act unlawfully if it failed to consider relevant guidance in the National Framework or misconstrued it.
- 50. Regulation 20 transposes the definitions of 'NHS Continuing Healthcare' (i.e. CHC) in the National Framework into Regulations 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"

51. The word 'care' is not defined in the RSR Regs or in the NHS Act 2006, 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 need for CHC assessments to be undertaken prior to eligibility decisions³³.

52. Regulation 21(2) of the RSR Regs provides:

³¹ As stated above, for the purposes of this chapter, predominantly ICBs. There may, of course, be questions of *which* commissioner is responsible for an individual patient, and thus their CHC eligibility assessment. For a full discussion, please see Chapter 13 on the responsible commissioner.

³² Bar a few amendments made in the present edition which is dated July 2022, this is substantively the most recent edition. The only substantial changes between May 2022 and July 2022 is that CCGs were replaced by ICBs as local decision makers.

³³ Other than in a Fast Track case as to which see para XX below.

"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"
- 53. The RSR Regs thus impose a statutory duty on the ICB to take reasonable steps to ensure a CHC assessment is carried out if it is aware either (a) that a person "may" have a need for CHC care or (b) that a person who has been found eligible for CHC may no longer be eligible. This duty is triggered if the ICB becomes aware of facts that suggests a patient is or could be eligible for CHC or there has been a change in the needs of a previously eligible patient such that the person may no longer be eligible.
- 54. ICBs are not under an absolute duty to carry out a CHC assessment. The duty is to take 'reasonable steps' with the aim of doing an assessment. Nonetheless, the National Framework anticipates the whole CHC assessment and decision-making process should be completed within 28 days, and that suggests that an ICB should act promptly once it is aware that someone may be eligible. If the patient actively seeks a CHC assessment, the use of the word "ensure" in the above duty suggests that the ICB is under a high level of duty promptly to complete the assessment³⁴.
- 55. 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).³⁵ Hence if a patient with capacity either refuses to be assessed for CHC or refuses to engage with a reassessment process (to determine continuing eligibility) the ICB can be placed in a difficult position. The National Framework³⁶ states that:

³⁴ In R (Elkundi) v Birmingham City Council [2022] EWCA Civ 601 the Court of Appeal decided that a duty "ensure" something happened imposed a "non-deferrable and unqualified, in that the duty is to secure that.." it did happen.
³⁵[1993] Fam 95.

³⁶ See page 28.

"If an individual with the relevant capacity refuses to participate in the NHS Continuing Healthcare assessment process, the Multi-Disciplinary Team (MDT) may consider relevant health and care records or existing assessments to determine the best way to meet the individual's needs and whether they are eligible for NHS Continuing Healthcare. The consequences of undertaking the NHS Continuing Healthcare assessment or review as a paper-based exercise should be carefully explained to the individual, including that this may affect the quality of the assessment, for example if the health and care records to be considered by the MDT are not up-to-date or accurate.³⁷

This part of the guidance may need to be considered carefully. The legal duty is to take "reasonable steps to ensure that an assessment of eligibility". If the patient refuses to engage, it may (depending on the circumstances be reasonable not to undertake an assessment. However, if the evidence is available in other forms (medical notes and previous assessments and can be lawfully accessed by the ICB³⁸), it may be reasonable to carry out the best assessment that is possible in the circumstances and then offer the patient a package of support. It may well be that a refusal to co-operate with an assessment cannot be equated to a refusal to accept support. If the patient is eligible for CHC and the ICB is attempting to do a reassessment (as it is recommended to do under the guidance) the patient cannot hold any veto by not co-operating or giving consent. The ICB will be fully within its rights to pursue the reassessment, drawing such inferences as appear to be appropriate from the patient's refusal to engage in the process. Ultimately, whatever the outcome of any assessment, an NHS patient who has capacity to make their own care and treatment decisions can refuse care or treatment that the ICB decides to offer to meet their reasonable requirements.

56. The information which can trigger the assessment duty can come from any source, including a local authority, provided there is enough information to lead the ICB to believe that the patient *may* have need for CHC. The duty to carry out a

³⁷ Para 75.

³⁸ The ICB will need to examine whether it is consistent with its data protection obligations to obtain special category information relating to the patient from clinicians treating the patient in the face of any actual opposition from the patient to the ICB seeing that information or any lack of consent from the patient. Whether information can be lawfully accessed by the ICB will depend on the particular circumstances of an individual case.

CHC assessment can thus arise whether there is a request by the patient (or their family) for an assessment or the information comes to the ICB from the GP, as part of a hospital discharge process or in any other way.

57. The wording of the Reg 21 duty appears to be deliberately framed to be 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 s9 of the Care Act 2014 (formerly s 47 of the NHSCCA 1990). The case-law suggests that there is a low threshold before the duty to carry out an assessment arises (see *R v Bristol CC ex p Penfold*³⁹). All that is needed to trigger a duty to carry out an assessment is for the ICB to have sufficient information that a patient 'may' be eligible for CHC.

Is a hospital inpatient entitled to seek a CHC assessment?

58. There is an understandable push to avoid delayed hospital discharges and, as part of that to ensure that all patients are discharged as soon as the patient does not have a clinical need for the services of an acute hospital. This is known as "Discharge to Assess" ("DtA") has moved the focus of assessment from the hospital to step-down care⁴⁰. This guidance states:

"Where people who are clinically optimised and do not require an acute hospital bed, but may still require care services are provided with short term, funded support to be discharged to their own home (where appropriate) or another community setting. Assessment for longer-term care and support needs is then undertaken in the most appropriate setting and at the right time for the person"

59. The National Framework recommends (but does not mandate) that assessments should be carried out after discharge. It states⁴¹:

^{(1997–98) 1} CCLR 315. In that case Scott Baker J said as follows: ""It seems to me that Parliament has expressed Section 47(1) in very clear terms. The opening words of the subsection, the first step in the three stage process, provide a very low threshold test. The reference is to community care services the authority may provide or arrange for. And the services are those of which the person may be in need. If that test is passed it is mandatory to carry out the assessment. The word shall emphasises that this is so. The discretionary element comes in at the third stage when the authority decides, in the light of the results of the assessment what, if any, services to provide".

⁴⁰ See for example https://www.nhs.uk/nhsengland/keogh-review/documents/quick-guides/quick-guide-discharge-to-access.pdf

⁴¹ See para 103

"For individuals leaving the acute hospital environment, it is best practice to screen for NHS Continuing Healthcare at the right time and in the right place for that individual. In the vast majority of cases this will be following discharge and after a period of recovery in a familiar setting or intermediate/rehabilitation placement. It should always be borne in mind that a screening, or an assessment of eligibility for NHS Continuing Healthcare that takes place in an acute hospital setting is unlikely to accurately reflect an individual's longer-term needs"

60. If a hospital patient is potentially eligible for CHC, then there is no part of the wording of the assessment duty under Reg 20 which can prevent the duty to assess arising⁴². This is confirmed in the DtA Guidance which provides that DtA must not lead to:

"Denying people the right to an assessment for NHS Continuing Healthcare (NHS CHC) if they may have a need for this⁴³"

61. Thus, it is highly likely to be unlawful (as well as contrary to the above Guidance) for an ICB to refuse to carry out a CHC assessment of a patient on the grounds that the patient is in hospital and CHC assessments should only take place after discharge.

Hospital discharge cases

62. As the National Framework sets out at para 97, 'eligibility for NHS Continuing Healthcare is assessed in two stages in most cases. The assessment process usually starts with a screening tool called the Checklist which, if positive, indicates that an individual requires full assessment for CHC. The assessment then involves a multidisciplinary team (MDT) undertaking a comprehensive assessment and evaluation of an individual's health and social care needs and reviewing evidence to make an assessment of eligibility for CHC using a standardised tool called a "Decision Support Tool" to help inform the decision.'

⁴² This issue was due to be determined by the Divisional Court in a case that was listed for trial in December 2022 where a patient was "stuck" in hospital because a care package could not be arranged and the ICB refused to do the CHC assessment whilst she was in hospital. The ICB backed down at the last minute and agreed to do the CHC assessment and so there was no judicial decision on the matter.

 $^{^{43}}$ That is consistent with para 20 of the decision of the High Court in R (JF) v NHS Sheffield Clinical Commissioning Group [2014] EWHC 1345 (Admin).

- 63. Patients are often assessed for their eligibility for CHC at the point that they are ready to be discharged from hospital. However, as the National Framework notes at para 100, 'Screening and assessment of eligibility for NHS Continuing Healthcare should be at the right time and location for the individual and when the individual's ongoing needs are clearer. The full assessment of eligibility should normally take place when the individual is in a community setting.' Paragraphs 101 to 108 of the National Framework clarify the position from the previous version of the guidance and set out the approach to be taken in such cases as follows:
 - "101. There is growing evidence that the most effective way to support people is to ensure they are discharged safely when they are clinically ready, with timely and appropriate recovery support if needed. An assessment of longer-term or end of life care needs should take place once they have reached a point of recovery, where it is possible to make an accurate assessment of their longer-term needs. This process is set out in the hospital discharge guidance. This may include screening for NHS Continuing Healthcare, depending on the individual's circumstances and the point at which their longer-term needs are clearer. In the vast majority of cases this will be following discharge and after a period of recovery at home.
 - 102. Multi-disciplinary discharge teams should work together when discharging people to manage risk carefully with the individual, and their unpaid carer, representative or advocate, as there can be negative consequences from decisions that are either too risk averse, or do not sufficiently identify the level of risk. At one end of the scale, people may be discharged onto pathways which result in care being over-prescribed; and at the other end, individuals may not receive the care and support they need to recover. Any onward care providers should be included early in the person's discharge planning. This allows more time for local capacity to be managed and suitable support to be put in place. People's care needs may also change, and there should be processes in place to ensure these needs are regularly reviewed and that the person is receiving appropriate care and support.

103. ICBs should ensure that local protocols are developed between themselves, other NHS bodies, local authorities and other relevant partners. These should set out each organisation's role and how responsibilities are to be exercised in relation to hospital discharge, including any arrangements for intermediate, reablement, rehabilitation or sub-acute care and arrangements for long-term care assessments including NHS Continuing Healthcare. In particular, ICBs should ensure (i.e. through contractual arrangements) that discharge policies with all providers are clear. Where appropriate, the ICB may wish to make provisions in its contract with the provider. There should be processes in place to identify those individuals for whom it is appropriate to undertake a screening for NHS Continuing Healthcare using the Checklist and, where the Checklist is positive, for full assessment of eligibility to be undertaken at the appropriate time and place.

104. For individuals leaving the acute hospital environment, it is best practice to screen for NHS Continuing Healthcare at the right time and in the right place for that individual. In the vast majority of cases this will be following discharge and after a period of recovery in a familiar setting or intermediate/rehabilitation placement. It should always be borne in mind that a screening, or an assessment of eligibility for NHS Continuing Healthcare that takes place in an acute hospital setting is unlikely to accurately reflect an individual's longer-term needs. This could be because, with appropriate support and opportunity, the individual has the potential to recover further in the near future. Another reason is that it may be difficult to make an accurate assessment of an individual's needs while they are in an acute services environment.

105. Where an individual is ready to be safely discharged from acute hospital it is very important that this should happen without delay. Therefore, the assessment process for NHS Continuing Healthcare should not be allowed to delay hospital discharge.

106. In order to 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 weeks or months. It might also include intermediate care or an interim package of support, preferably in an individual's own home. In such situations, assessment of eligibility for NHS Continuing Healthcare, if still required, should be undertaken when an accurate assessment of ongoing needs can be made. The interim services should continue until it has been decided whether or not the individual has a need for NHS Continuing Healthcare (refer to paragraph 107). There must be no gap in the provision of appropriate support to meet the individual's needs. It is important that there are clear local protocols setting out where responsibility for meeting an individual's needs lies, including who is responsible for funding their care and support.

107. In the vast majority of cases, CHC assessments should take place in community settings. There may be rare circumstances where assessments may take place in an acute hospital environment. In addition, ICBs and their partner organisations should ensure appropriate processes and pathways exist for individuals who may have a need for NHS Continuing Healthcare, for example:

- (a) where the individual has an existing package or placement which all relevant parties agree can still safely and appropriately meet their needs without any changes, then they should be discharged back to this placement and/or package under existing funding arrangements. In such circumstances any screening for NHS Continuing Healthcare, if required, should take place within six weeks of the individual returning to the place from which they were admitted to hospital. If this screening results in a full assessment of eligibility and the individual is found eligible for NHS Continuing Healthcare through this particular assessment, then any necessary re-imbursement should apply back to the date of discharge;
- (b) a decision is made to provide interim NHS-funded services to support the individual after discharge. This may allow individuals to reach a better point of recovery and rehabilitation in the community before their longer-term needs are assessed. In such a case, before the interim NHSfunded services come to an end, screening, if required, for NHS Continuing Healthcare should take place through use of the Checklist

- and, where appropriate, the full MDT process using the DST (i.e. an assessment of eligibility);
- (c) a 'negative' Checklist is completed in an acute hospital (i.e. the person does not have a need for NHS Continuing Healthcare);
- (d) a 'positive' Checklist is completed in an acute hospital and interim NHS-funded services are put in place to support the individual after discharge until it is either determined that they no longer require a full assessment (because a further Checklist has been completed which is now negative) or a full assessment of eligibility for NHS Continuing Healthcare is completed;
- (e) a 'positive' Checklist is completed in acute hospital and a full assessment of eligibility for NHS Continuing Healthcare takes place before discharge. In a small number of circumstances, it may be decided to go directly to a full assessment within the acute hospital, without the need for a Checklist. ICBs are reminded that if an individual's needs change in a short time frame between a positive Checklist and a full assessment of eligibility taking place, it is legitimate to undertake a second Checklist, rather than necessarily proceeding to full assessment of eligibility for NHS Continuing Healthcare. The individual should be kept fully informed of the changed position"
- 64. The latest version of the guidance rectifies some arguable errors in the previous version by clarifying that: (i) any 'interim' or 'intermediate' care or package of support, including where that care is designed to provide therapy or rehabilitation that will potentially improve a patient's position and thus diminish their need for CHC, can (depending on locally agreed policies) be <u>funded</u> by the NHS; and (ii) where a patient is discharged to an existing package or placement before being screened and/or assessed for CHC eligibility, and is later found eligible, they should be reimbursed for the costs of that care back to the date of discharge. There is an argument that the latter approach would still mean that an ICB was in breach of its statutory duty under regulation 21 of the RSR Regs 2012, by failing to assess someone who 'may' have a need for CHC in hospital. However, the guidance now goes some way in mitigating the essential practical problem with this approach, which is that it may, wrongly, shift the costs of care home and social care fees onto a patient, depending on means-testing.

The CHC checklist as an initial screening tool

65. As the National Framework makes clear, 'the Checklist is the NHS Continuing Healthcare screening tool which can be used in a variety of settings to help practitioners identify individuals who may need a full assessment of eligibility for NHS Continuing Healthcare.' If the ICB has a legal duty to conduct a CHC assessment, the first step is decide whether 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) of the RSR Regs 2012 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 1 March 2018 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"
- 66. 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 trained in its use⁴⁴. The purpose of the checklist is to help practitioners identify people who need a full assessment for NHS CHC and those who do 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 RSR Regs 2012 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 usually a sound basis for an ICB concluding that the person is not eligible for CHC.

⁴⁴ See para 122 of National Framework.

- 67. The Checklist has 11 care domains broken down into three levels: A, B or C (where A represents a high level of care need, and C is a low level of care need). The outcome of the Checklist depends on the number of As, Bs, and Cs identified.
- 68. There may be exceptional circumstances where a full consideration for NHS CHC is necessary even though the individual does not appear to meet the indicated threshold. Generally, however, if the patient does not pass the above tests, then the ICB 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 get through the initial screening but will not be entitled to fully funded CHC.
- 69. 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, as well as sections requiring a brief description of any needs (and sources of evidence) under each domain. Completing the form with reasons is a legal requirement under the regulations.
- 70. Paras 131-133 of the *National Framework* set out the process where there has been a negative checklist and paras 134-137 set out the process where there has been a positive checklist.
- 71. The National Framework also provides a number of scenarios where it suggests 'it is not necessary to complete a Checklist', including:
 - (i) It is clear to practitioners working in the health and care system that there is no need for NHS Continuing Healthcare at this point in time. Where appropriate/relevant this decision and its reasons should be recorded. If there is doubt between practitioners a Checklist should be undertaken;
 - (ii) The individual has short-term health care needs or is recovering from a temporary condition and has not yet reached their optimum potential (if there is doubt between practitioners about the short-term nature of the needs it may be necessary to complete a Checklist). See paragraphs 96-103 for how NHS Continuing Healthcare may interact with hospital discharge;
 - (iii) It has been agreed by the ICB that the individual should be referred directly for full assessment of eligibility for NHS Continuing Healthcare;

- (iv) The individual has a rapidly deteriorating condition and may be entering a terminal phase – in these situations the Fast Track Pathway Tool should be used instead of the Checklist;
- (v) An individual is receiving services under Section 117 of the Mental Health Act that are meeting all of their assessed needs; and
- (vi) It has previously been decided that the individual is not eligible for NHS Continuing Healthcare and it is clear that there has been no change in needs.

The full CHC assessment process.

- 72. Once an individual has been referred for a full assessment of eligibility for NHS Continuing Healthcare (following use of the Checklist or, if a Checklist is not used in an individual case, following direct referral for full consideration), then, the ICB must appoint a multidisciplinary team ("MDT") to assess whether the individual has a primary health need using the Decision Support Tool ("DST")⁴⁵. Regulation 21(5) of the RSR Regs describes the process an ICB must follow when undertaking the full CHC assessment process. It provides:
 - "(5) 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 1st March 2018; 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"

⁴⁵ See https://www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool

- 73. The Guidance recommends each ICB 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 at PG20.⁴⁶
- 74. There are a number of points to note about the MDT. It is defined in reg 21(13) of the RSR Regs 2012 to mean a team consisting of, at least, 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 an adult's need for care and support under section 9 of the Care Act 2014 (assessment of an adult's needs for care and support).
- 75. The National Framework recommends that it is best practice to include a professional with a social care background as part of the MDT, usually 'who are knowledgeable about the individual's health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual', but it is lawful to have an MDT with two different healthcare professionals.⁴⁷ The role of the MDT is to carry out the CHC assessment. However, the MDT is not the final decision-making body as to whether a patient qualifies for CHC. The team's role is to complete the assessment process and to provide the information to an ICB appointed decision maker (or decision-making panel), and thus support the ICB decision-maker to decide whether the patient is eligible for CHC. The MDT should complete the DST paperwork, including noting their own membership, along with a full record made of any recommendations made by the MDT and the reasons for any such recommendations. The MDT is required to meet and make decisions using the DST.⁴⁸ The National Framework describes the DST as follows:

"151. The Decision Support Tool (DST) has been developed to aid consistent decision making. The DST supports practitioners in identifying the

⁴⁶See National Framework p133-134.

⁴⁷See National Framework para 140-141.

⁴⁸ The present version of the DST is dated July 2022 and is available at https://assets.publishing.service.gov.uk/media/635171fee90e07768d7f926c/NHS-continuing-healthcare-decision-support-tool-referral-form.pdf.

individual's needs. This, combined with practitioners' skills, knowledge and professional judgement, should enable them to apply the primary health need test in practice.

152. The DST is not an assessment of needs in itself. Rather, it is a way of bringing together and applying evidence in a single practical format, to facilitate consistent, evidence-based assessment regarding recommendations for NHS Continuing Healthcare eligibility. The evidence and rationale for the recommendation should be accurately and fully recorded.

...

154. The purpose of the DST is to help identify eligibility for NHS Continuing Healthcare. It is designed to collate and present the information from the assessments of need in a way that assists consistent decision-making regarding NHS Continuing Healthcare eligibility. The DST is a national tool and should not be altered"

76. The National Framework strongly advises against a 'virtual' meeting or the members of the MDT filling in the forms separately without meeting. It provides:⁴⁹

"PG 26 What happens if the coordinator is unable to engage relevant professionals to attend an MDT meeting?

26.1 ICBs should not make decisions on eligibility in the absence of an MDT recommendation, unless exceptional circumstances require an urgent decision to be made.

26.2 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

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⁴⁹ See *National Framework* p138-139.

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 ICB 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.

26.3 Care should be taken to ensure that alternative approaches for MDT participation still enable the individual being assessed to fully participate in the process.

26.4 If, even after having followed the above processes, there are still difficulties with the participation of, or obtaining assessment information from, a specific professional, ICBs 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. ICBs should record the attempts to secure participation.

26.5 In order to ensure effective MDT decision-making, ICBs should:

- have arrangements in place for coordinators to obtain senior support to secure participation of other practitioners where necessary
- consider agreeing protocols on MDT participation with organisations that frequently have staff who participate in MDTs"
- 77. In practice this means that Guidance recommends the MDT should meet in person. However, whether it meets in person or virtually, the MDT must 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*⁵⁰ contains the following guidance about the MDT assessment:

⁵⁰See National Framework pp134-135.

"PG 21 What are the elements of a good multidisciplinary assessment of needs?

21.1 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. Simply gathering information will not provide the rationale for any eligibility recommendation; a recommendation that simply provides a judgement without the necessary information will not provide the evidence for any subsequent 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.

21.2 As a minimum a good quality multidisciplinary assessment of an individual's health and social care needs will be:

- 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
- 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
- include 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 if possible
- 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.
- 21.3 Effective assessment processes and documentation are key to making 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.
- 21.4 ICBs and local authorities should consider agreeing joint models of assessment documentation and having regular training or awareness events to support them.
- 21.5 This will require the gathering and scrutiny of all available and appropriate evidence, whether written or oral, including that from the GP, hospital (nursing, medical, mental health, therapies, etc.), professionals with relevant skills, knowledge and expertise, community nursing services, care home provider, local authority records, assessments, Checklists, DSTs, records of deliberations of MDTs, panels, etc., as well as any information submitted by the individual concerned; compilation of a robust and accurate identification of the care needs; audit of attempts to gather any records said not to be available; involvement of the individual or their representative as far as possible, including the opportunity for them to contribute and to comment on information"
- 78. 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, PG22 of the *National Framework* suggests the following sources:

"PG 22 What are the potential sources of information/evidence? (NB: this is not an exhaustive list)

• Health needs assessment

- Needs assessment (under the Care Act 2014)
- 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"
- 79. 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.
- 80. One of the key elements in the CHC process is to attempt to secure consistency of decision-making across an ICB and between ICBs. As explained above, the variations between areas led to complaints of a 'post-code lottery' around which patients are and are not eligible for CHC, depending on the approach taken by a local NHS commissioner. Discrepancies between decisions made by different NHS bodies was one of the primary criticisms of the 2003 PHSO Report. That led to a concern to seek to achieve as much uniformity as possible across the English NHS. That desire 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:

"PG28: What process should be used by MDTs to ensure consistency when completing the DST?

28.1 Whilst local conditions and therefore local processes will vary, the following elements are recommended as being core to achieving consistency:

- 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.
- 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.
- 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.
- 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.
- 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.

- 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 (refer to paragraphs 151-172 of the National Framework relating to the completion of the DST and making eligibility recommendations).
- The recommendation should then be presented to the ICB, who should accept this, except in exceptional circumstances. These circumstances could for example include insufficient evidence to make a recommendation or incomplete domains.
- If the ICB does not accept the MDT recommendation (refer to Practice Guidance note 39 for circumstances when this can happen) it should refer the DST back to the MDT identifying the issues to be addressed. The coordinator for the individual case has a critical role in ensuring that any deficiencies in the MDT assessment and recommendation are fully addressed in order to avoid further delay in decision-making. The coordinator should be satisfied that there is sufficient evidence and a clear rationale to support the recommendation before resubmitting the DST. Once the completed DST has been re-presented to the ICB, the ICB should then accept the recommendation (except in exceptional circumstances). The ICB remains responsible, and accountable for, the final eligibility decision and should avoid repeatedly returning a DST to the MDT.
- 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.

28.2 This whole process should usually be completed within 28 (calendar) days. This timescale is measured from the date the ICB 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"

How should the MDT should use the DST to score levels of need?

- 81. The primary purpose of the MDT assessment process is to understand and assess the seriousness of the needs of a person, and thus enable the ICB to make an informed decision as to whether the person has a primary health need. The *National Framework* explains this purpose as follows:
 - "155. The DST is designed to ensure that the full range of factors that have a bearing on an individual's eligibility are taken into account in reaching the decision, irrespective of client group or diagnosis. The tool provides practitioners with a method of bringing together and recording the various needs in 12 'care domains', or generic areas of need. Each domain is broken down into a number of levels. The levels represent a hierarchy from the lowest to the highest possible level of need (and support required) such that, whatever the extent of the need within a given domain, it should be possible to locate this within the descriptors provided.

156. The care domains are:

- 1. Breathing
- 2. Nutrition
- 3. Continence
- 4. Skin Integrity
- 5. Mobility
- 6. Communication
- 7. Psychological & Emotional needs
- 8. Cognition
- 9. Behaviour
- 10. Drug therapies and medication
- 11. Altered states of consciousness
- 12. Other significant care needs

- 157. Completion of the tool should result in a comprehensive picture of the individual's needs that captures their nature, and their complexity, intensity and/or unpredictability and thus the quality and/or quantity (including continuity) of care required to meet the individual's needs..."
- 82. The MDT is required to assess the level of the person's "need" for care and support in relation to each care domain. The level of need for any care domain can be assessed at:
 - No needs;
 - Low;
 - Moderate;
 - High;
 - Severe;
 - Priority (but only for four of the domains: behaviour, breathing, drugtherapies or altered states of consciousness domains).

How should the MDT approach the assessment of "need" when that need is well managed at present?

- 83. One of the most difficult issues in practice is assessing the level of a 'need' demonstrated by a patient in a case where medical and social care interventions mean that the need is being effectively managed and thus the potential adverse clinical consequences of the clinical condition are avoided. Hence, for example, a patient may have a medical condition which means that the patient is at a high risk of developing threats to their skin integrity but a good management plan means that this has been avoided for months or years. The National Framework recognises that the person will still have this "need" even if good care management means that the need is a present problem. It gives the following guidance:
 - "162. The decision-making rationale should not marginalise a need just because it is 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, such that the active

management of this need is reduced or no longer required, will this have a bearing on NHS Continuing Healthcare eligibility.

- 163. An example of the application of the well-managed needs principle 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.
- 164. 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 diary over a suitable period of time to demonstrate the nature and frequency of the needs and interventions, and their effectiveness.
- 165. 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.
- 166. It is not intended that this principle should be applied in such a way that well controlled conditions should be recorded as if medication or other routine care or support was not present (refer to Practice Guidance note 23 for how the well managed needs principle should be applied). The multi-disciplinary team should give due regard to well-controlled conditions when considering the four characteristics of need and making an eligibility recommendation on primary health need (refer to paragraph 60)"
- 84. This passage of the guidance suggests that 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'51.

Managing disagreements amongst members of the MDT.

85. As the assessment of need is a matter of professional clinical judgment, it is inevitable that assessors may have different views 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 reconciled, the higher score by an assessor must be treated as the score of the panel. PG32 in the National Framework provides further guidance on this scenario as follows:

"32.1 The DST (paragraph 25 of the user notes) 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. Additional evidence may be sought, although this should not prolong the 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 ICB can note this when verifying recommendations.

32.2 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 ICB 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 further training may be offered.

⁵¹ The DST is designed to largely take this balancing of needs into account and for the most part, it works. Significant input in one area balances the lower need consequent upon that in another.

32.3 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 ICBs' 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."

Feeding in views on domain scores from the patient and members of the patient's family.

86. The patient or members of the patient's family are entitled to be present at the MDT meeting and the MDT are required to consider and give appropriate weight to their views because they are likely to have considerable personal knowledge of the patient over an extended period and will have valuable perspectives on the patient's needs and how they are best managed⁵². However, as they are not members of the MDT, their views on the severity of a domain cannot be decisive. PG33 explains:

"PG33: What happens if the individual 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 (refer to paragraphs 139-143 of the National Framework regarding the composition of the MDT). The approach described in Practice Guidance note 34 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"

⁵² Practitioners also need to bear in mind that patients and their families often have a financial incentive to secure a positive CHC eligibility decision and, unlike MDT members, will rarely have knowledge of a large number of other cases and thus may not be able to assess the relative severity of a person's condition as compared to other patients suffering from the same underlying condition, their associated needs and whether this amounts to a primary health need.

How should the MDT use the domain scores to lead to a recommendation on whether the person has a primary health need?

- 87. Once the MDT has collected all the relevant information, sought the views of the patient and family, and carefully undertaken the domain scoring exercise, it then needs to make a recommendation as to whether the person has a primary health need. At this point the process moves from a subtle, multi-factorial assessment to a binary conclusion.
- 88. The most straightforward way in which the MDT can make a positive recommendation of CHC eligibility for the MDT to find that the person has sufficient needs that the terms of para 35 of the DST are satisfied. The DST provides at para 35:

"A clear recommendation (and decision) of eligibility for NHS continuing healthcare would be expected in each of the following cases:

- a level of priority needs in any 1 of the 4 domains that carry this level
- a total of 2 or more incidences of identified severe needs across all care domains"
- 89. The four domain "needs" where the person can be scored as having a "Priority" need⁵³ are:
 - Breathing
 - Behaviour
 - Drug Therapies
 - Altered states of consciousness
- 90. The wording of the DST ("would be expected") makes it clear that a finding of a priority need does not automatically lead to a finding that the person has a primary health need. The MDT still has to exercise its clinical judgment and it is possible (depending on the precise clinical situation of a person) for a person to have to have either a priority level of need in a single domain or two or more incidences of severe needs and yet not be found to have a primary health need. However, if that is the MDT's conclusion, the MDT would need to formulate clear reasons to reach

⁵³ See para 4 of the DST.

that conclusion⁵⁴ or, if that decision was reached by the ICB decision maker, clear reasons would need to be formulated.

- 91. Equally, the fact that a person is not assessed to have either a priority level of need in a single domain or two or more incidences of severe needs does not rule out a person having a primary health need. The DST Guidance states:
 - "36. Where either of the following criteria are met:
 - a severe level need combined with needs in a number of other domains
 - a number of domains with high and/or moderate needs...
 - 37. ...this may also, depending on the combination of needs, indicate a primary health need, and therefore careful consideration needs to be given to the eligibility decision and clear reasons recorded if the decision is that the person does not have a primary health need.
 - 38. In all cases, the overall need, the interactions between needs in different care domains and the evidence from risk assessments should be taken into account in determining whether a recommendation of eligibility for NHS continuing healthcare should be made.

It is not possible to equate a number of incidences of one level with a number of incidences of another level – as in, for example, '2 moderates equals one high'. The judgement whether an individual has a primary health need must be based on what the evidence indicates about the nature and/or complexity and/or intensity and/or unpredictability of the individual's needs"

92. In making its assessment, the MDT are also required⁵⁵ to consider the nature, intensity, complexity and unpredictability of the person's condition as part of an

⁵⁴ The authors are aware that this situation arises not infrequently in practice where a person is assessed to have a priority need in the "behaviour" domain but that the management of that behaviour is, in practice, a matter for highly skilled social care teams as opposed to the person's behaviour being medically managed. The test for a priority score is that "'Challenging' behaviour of a severity and/or frequency and/or unpredictability that presents an immediate and serious risk to self, others or property. The risks are so serious that they require access to an immediate and skilled response at all times for safe care". In such a case it can be legitimate for an ICB to conclude that, notwithstanding the person has a priority score for challenging behaviour, the lack of medical input into the management of the person's behaviour means that the person does not have a primary <u>health</u> need.

⁵⁵ See page 43 of the DST form.

overall reasoning process to determine whether the person has a primary health need. The National Framework describes these factors at para 60 as follows:

- Nature: This describes the particular characteristics of an individual's needs (which can include physical, mental health or psychological needs) and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them.
- Intensity: This relates both to the extent ('quantity') and severity ('degree') of the needs and to the support required to meet them, including the need for sustained/ongoing care ('continuity').
- Complexity: This is concerned with how the needs present and interact to increase the skill required to monitor the symptoms, treat the condition(s) and/or manage the care. This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need.
- Unpredictability: This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the person's health if adequate and timely care is not provided. An individual with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition"
- 93. The members of the MDT are required to use their professional clinical skills to come to an overall assessment as to whether the person has a primary health need, having regard to all these factors. The Guidance states at para 167:

"The MDT is required to make a recommendation to the ICB as to whether or not the individual has a primary health need, bearing in mind that where the ICB decides that the individual has a primary health need they are eligible for NHS Continuing Healthcare (refer to Practice Guidance note 34). In coming to this recommendation, the MDT should work collectively using professional judgement"

94. The question of the MDT is thus whether the totality of the clinical picture leads to the conclusion that the person has a primary health need. The decision needs to be recorded in the DST form with reasons given for the recommendation.

Consultation with social services.

- 95. Regulation 22(1) of the RSR Regs provides that ICBs must, as far as reasonably practicable, consult with social services before making a final decision about whether a patient qualifies for CHC and co-operate with the relevant social services authority in arranging for persons to participate in an MDT team (for example where there is a social worker on the team). There is a duty on social services departments to provide advice and assistance to ICBs when they are consulted⁵⁶. 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 ICB. The consultation stage should happen after the completion of MDT assessment but before the eligibility decision is made⁵⁷.
- 96. The ICB 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), data protection legislation should not prevent the flow of relevant clinical information between the local authority. The ICB are probably entitled to rely on the statutory duty to consult under reg 22 of the RSR Regs 2012 to justify the disclosure of sensitive personal data about the patient to the local authority (at least in the absence of objections by the patient). It thus appears that, unless there are very special circumstances, the local authority is entitled to see all the case papers concerning the patient to assist them to respond to the application for CHC.
- 97. However, the local authority does not have an automatic right to see patient related information for other purposes, such as following up any concerns they may have about other service users. ICB staff should seek advice if they are

⁵⁷ see National Framework paras 26-31 for guidance on the roles and responsibilities of local authorities.

⁵⁶ See reg 3 of the Care and Support (Provision of Health Services) Regulations 2014

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.

98. The National Framework provides the following guidance on processing an individual's data:

"Processing an individual's personal data

- 80. ICBs must comply with their legal obligations when handling, processing and sharing an individual's personal data. For further guidance on information sharing and NHS Continuing Healthcare, please see Practice Guidance notes 5 and 6.
- 81. It is necessary to obtain an individual's explicit consent before sharing any personal data with a third party such as a family member, friend, advocate, and/or other representative.
- 82. However, it is not necessary to seek consent from an individual in order to share their personal data where this is necessary for the purposes of their NHS Continuing Healthcare assessment (and subsequent reviews) or the provision or management of their health or social care treatment between health and social care professionals.
- 83. Nevertheless, in order to comply with the UK GDPR, it is necessary to inform the individual how and with whom their personal data will be shared as part of the assessment process or to arrange appropriate care and support.
- 84. An individual with the relevant capacity, who is to be assessed for NHS Continuing Healthcare, should be provided with relevant information about the process. This will enable them to make an informed decision regarding their consent to the sharing of their personal data with a third party such as a family member, friend, advocate, and/or other representative as part of the assessment for NHS Continuing Healthcare. To facilitate this process, it may be appropriate to discuss any concerns the individual may have and alleviate

any relevant concerns, for example that an individual's personal information will only be shared with third parties as appropriate. If an individual with the relevant capacity does not consent to the sharing of their personal data with third parties other than health and social care professionals, such as family, friends, advocates, and/or other representatives, the potential consequences of the decision should be carefully explained. The involvement and contribution of family members and representatives is usually key to a person-centred NHS Continuing Healthcare assessment, meaning the quality of this assessment may be affected if information cannot be shared with these third parties"

- 99. 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 ICB is the sole decision-maker on CHC eligibility as the Court of Appeal confirmed in *R* (St Helens Borough Council) v Manchester PCT and another.⁵⁸
- 100. The ICB must take any views expressed by local authority colleagues into account when taking the CHC eligibility decision. Tensions between the ICB and the local authority can mean that the ICBG ends up disagreeing with the local authority's views on the right outcome of an individual case. The local authority may press the case that a patient should be found eligible for CHC and thus seek to ensure that a patient's ongoing care is NHS funded (usually supported by the patient and/or the family). However, it is not unknown for the ICB to disagree with views strongly expressed by local authority colleagues. Any such disagreement should not prevent the ICB making a decision because the duty on the ICB under the regulations is to *consult* the local authority. This process 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 ICBs and local authorities are considered below.
- 101. If the local authority fails to respond to a request to provide input into the CHC process relating to a particular patient, the ICB are entitled to press ahead to the decision-making phase without the local authority input.

⁵⁸[2008] EWCA Civ 931, (2008) 11 CCLR 774.

Decision making on CHC eligibility by the ICB.

- 102. The MDT makes recommendations but the decision maker as to whether a person is eligible for CHC is the ICB. There is considerable flexibility pursuant to section 65Z5 of the NHS Act 2006 and the NHS England guidance to ICBs on model constitutions⁵⁹ to permit ICBs to delegate decision-making to a committee that includes individuals who are not employed by the ICB Thus, the ICB panel could include colleagues from social services or patient user groups, provided that the body is constituted as a committee of the ICB.
- 103. The membership, terms of reference and decision-making powers of the panel should be approved by the ICB governing body. Many ICBs 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 ICB have a right of veto or constitute a majority for a vote on the issue of eligibility. The ICB should not leave itself in a position where ICB staff are unable to take a decision that a patient is or is not eligible for CHC.
- 104. The ICB decision maker (whether an individual or a panel) is required to follow the statutory decision-making process in Reg 21 RSR Regs in order to decide if a person has a primary health need. If the ICB finds that the person has primary health need, a decision must be made that the person is eligible for CHC because reg 21(6) RSR Regs 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"

The two separate routes by which an ICB can come to a decision that the person has a primary health need.

105. Properly analysed⁶⁰, the statutory decision-making process under Reg 21 of the RSR Regs can lead to a decision that a person has a primary health need and

⁵⁹ Available here: https://www.england.nhs.uk/wp-content/uploads/2021/06/B1551--Guidance-to-Clinical-Commissioning-Groups-on-the-preparation-of-Integrated-Care-Board-constitutions-.pdf.

⁶⁰ These separate routes for positive decision making on eligibility arise from the language used by Reg 21. This is implicit in the National Framework and the DST but has not been made explicit.

hence is eligible for CHC by one of two routes. ICB decision makers need to be clear whether:

- (c) The person is found eligible or is found eligible for CHC by route 1; or
- (d) The person is found not to be eligible for CHC by route 1, but is found to be eligible for CHC by route 2; or
- (e) The person is not eligible for CHC because they do not satisfy the tests for route 1 or route 2.
- 106. The tests under the statutory scheme are not straightforward and thus both the MDT and ICB decision makers should ensure that their paperwork makes it clear that both routes have been considered and which route, if either, has been followed to make a positive recommendation or decision on CHC eligibility.
- 107. Guidance is provided in PG40 about the role that ICBs are expected to fulfil in making CHC decisions. It provides:

"PG 40 How should ICBs fulfil their duty to make final eligibility decisions for NHS Continuing Healthcare?

- 40.1 The National Framework makes it clear that ICBs should not delegate their final decision-making function in relation to eligibility for NHS Continuing Healthcare. ICBs remain legally responsible for all such decisions even where they have authorised another body to carry out assessment functions on their behalf. ICBs have a number of options as to how to fulfil this responsibility. For example, they might choose to use one, or a combination of, the following:
- appoint (or jointly appoint) an employee (or employees) to work within the organisation carrying out the assessment functions such that this member of staff has authority to make eligibility decisions as an employee of the ICB with clear lines of authority and accountability within the ICB for undertaking this role
- identify an employee (or employees), within the ICB to make eligibility decisions regarding NHS Continuing Healthcare having received the completed assessments and recommendations from the organisation

- carrying out the NHS Continuing Healthcare assessment function on behalf of the ICB
- use a verification committee or 'panel' as a formal sub-committee of the ICB with delegated responsibility for decision making in relation to NHS Continuing Healthcare eligibility

40.2 Whatever arrangements the ICB chooses, it must be remembered that the National Framework places a strong emphasis on the MDT recommendation regarding eligibility for NHS Continuing Healthcare and states that '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 (refer to paragraph 176 of the National Framework). Any model for final ratification must respect this requirement and also the requirement that 'the final eligibility decision should be independent of budgetary constraints' (refer to paragraph 176 of the National Framework). It is vital that all arrangements for verifying recommendations and for making the final eligibility decisions are timely and efficient and do not result in delays, particularly where the individual concerned is awaiting transfer of care from an acute hospital setting"

108. This part of the Guidance is perhaps questionable because, if the statutory scheme in the RSR Regs 2012 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. There is nothing in the RSR Regs to support this "exceptionality" approach. In contrast regulation 23(8) of the RSR Regs provides that an ICB 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 unless it finds there are exceptional circumstances.

Route 1: Eligibility based on a person's needs.

109. The MDT is required to make a recommendation on CHC eligibility based on outcome of the DST process. Reg 21(5)(b) provides that:

"a relevant body must ensure that ... 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"

110. The National Framework makes it clear that, in making the decision whether a person has a primary health need, considerable weight has to be given to the recommendations of the MDT. It states at para 173:

"ICBs are responsible for decision making regarding NHS Continuing Healthcare eligibility, based on the recommendation made by the multidisciplinary team in accordance with the process set out in this National Framework. Only in exceptional circumstances, and for clearly articulated reasons, should the multidisciplinary team's recommendation not be followed"

111. The ICB is, of course, not obliged to accept the MDT recommendation without question and can ask further questions or raise concerns about anything in the MDT report. Para 176 of the National Framework provides:

"ICBs may choose to verify the multidisciplinary team's recommendation in a number of different ways. It is expected that whether the verification is done by an individual or by a panel, this process should not be used as a gate-keeping function or for financial control. A decision not to accept the multidisciplinary team's recommendation should never be made by one person acting unilaterally. The final eligibility decision should be independent of budgetary constraints, and finance officers should not be part of a decision-making process"

- 112. Thus, the first question for an ICB panel is whether, based on the recommendations of the MDT, the person has a primary health need based on their presenting needs alone. If the ICB decides that the person does have a primary health need on that basis, Reg 21(7) provides that the ICB is also required to decide that the person is eligible for CHC.
- 113. Unfortunately, this part of the Guidance does not appear to recognise the potential complexity of the decision making-process that the ICB is required to follow because it does not distinguish between a decision that a person has a primary health need based on the person's presenting condition alone and a decision that a person has a primary health need based on the tests under Reg 21(7) of the RSR Regs. The tests under Reg 21(7) provide for the second route by which a person can become eligible for CHC.

Route 2: The statutory deeming route under reg 21(7) RSR Regs to a finding of CHC eligibility.

- 114. If the ICB considers that, having regard to the tests set out in route 1, the person does not have a primary health need, the next question for the ICB is whether the person should be deemed to have a primary health need as a result of the tests in Reg 21(7) RSR Regs. Reg 21(7) RSR Regs creates an alternative route by which a person can become eligible for CHC where, in summary, the overall clinical picture means that sufficient of the person's needs lie on the NHS side of the NHS/social care divide that the person should be treated as being eligible for CHC.
- 115. As the complicated history of CHC decision making set out above shows, people with long term disabilities usually have needs which predominantly lie on the social care side of the NHS/social care divide. Where this happens, the majority of the person's care falls within services provided by the local authority under the Care Act 2014 ("CA 2014"). However, even if the vast majority of a person's needs are met by social care services, the person may also have an occasional or regular need for nursing care or other NHS services (namely from support by NHS clinical staff). Where someone needs a high level of medical input into their care, they are treated as being eligible for CHC.
- 116. That approach is logical in theory, but it raises the difficult question as to how much medical input a disabled person should need from nurses or other NHS

professionals before the person should be deemed to be eligible for CHC. Every disabled person will need GP services, but a need for a normal level of GP services (of itself) will not lead to an entitlement to CHC. However, where a person also needs services from a District Nurse, a physiotherapist or regular input from their local NHS hospital, the level of medical input can mean that the person's overall needs are sufficiently "medical" that the person should be deemed to be eligible for CHC. NHS and social care policy makers (and the courts) have long struggled with attempting to define the point at which the quantity and/or quality of the NHS services needed by a person who is supported outside of a hospital environment mean that the person's overall needs should be treated as falling on the NHS side of the NHS/social care divide, and thus a package of support to meet their needs should be funded by the NHS. This was one of the issues that the Court of Appeal were struggling to define in *Coughlan* and a measure of their thinking is carried through into the set of statutory tests that ICB decision makers are now required to apply.

117. The NHS/social care divide is now, in part, set out in statute in the CA 2014 and the RSR Regs. S22(1) of the CA 2014 provides:

"A local authority may not meet needs under sections 18 to 20 by providing or arranging for the provision of a service or facility that is required to be provided under the National Health Service Act 2006 unless—

- (a) doing so would be merely incidental or ancillary to doing something else to meet needs under those sections, and
- (b) the service or facility in question would be of a nature that the local authority could be expected to provide"
- 118. The purpose of this test is to define a range of health-type services that social services authorities are prohibited from being able to provide as a part of a package of social care under the CA 2014. Thus, if a person requires a service which comes within s22(1) and is not exempted by the provisos in sub-paras (a) and (b), a local authority is prohibited by law from funding the provision of that service.

- 119. The first question under s22(1) CA 2014 is whether the service is one which is "required" to be provided under the NHSA 2006. An ICB (and NHS England) has considerable discretion under s3 and 3A NHSA 2006 to decide what services to provide to a person who has medical needs. However, where an ICB has adopted a local policy which provides that it will provide a specific service, any patient with relevant needs has a legal right to access those services. Accordingly, it is suggested that such a service will come within s22(1) CA 2014⁶¹. If a service comes within s22(1), the local authority is prohibited from providing that service unless both of the tests in (a) and (b) are satisfied. Those tests are that the services in question are both incidental or ancillary to doing something else to meet the person's needs and are of a nature that the local authority could be expected to provide. This is a fact sensitive decision for the local authority but, where it can be shown that specific services are required to be provided by the NHS (such as for example GP services or the management of complex medications by a nurse) this test is highly likely to be met and thus the local authority is prohibited from providing those services as part of a social care package⁶².
- 120. S22(3) and (8) are supplementary to the general rule in in s22(1) and contain specific provisions relating to services by registered nurses. They provide:
 - "(3) A local authority may not meet needs under sections 18 to 20 by providing or arranging for the provision of nursing care by a registered nurse
 - (8) A reference to the provision of nursing care by a registered nurse is a reference to the provision by a registered nurse of a service involving—
 (a) the provision of care, or
 - (b) the planning, supervision or delegation of the provision of care, other than a service which, having regard to its nature and the circumstances in which it is provided, does not need to be provided by a registered nurse"

⁶¹ S22(2)(b) provides that Regulations can be made specifying the "types of services or facilities which may not be provided or the provision of which may not be arranged by a local authority, or circumstances in which such services or facilities may not be so provided or the provision of which may not be so arranged" but no such Regs have been made.

⁶² There are provisions in S22 for prohibited care to be provided by a local authority with the consent of the ICB or in an emergency.

- 121. Thus, in summary, if a disabled person who is in receipt of social care under the Care Act 2014 requires the services of a registered nurse as part of their care, that is a service which cannot be funded by the local authority.
- 122. The provisions in the CA 2014 are, to an extent (but not exactly) mirrored in the tests under the RSR Regs. R21(7) provides:
 - "(7) 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"

123. Reg 21(7) of the RSR Regs operates as a statutory deeming provision ⁶³. A statutory deeming provision requires an administrative decision maker to assume a statutory fiction when making decisions ⁶⁴. The "fiction" in this case is that a person has a primary health need when, based solely on the person's clinical indicators, it could not be said that the person has a primary health need. That fiction is needed to ensure that a person does not have needs which are too extensive that they cannot properly be delivered by a local authority in discharge of its social care duties under the CA 2014 but are not so extensive that the person qualifies for CHC. That would potentially create a "gap" where the person fell between the NHS and social care provisions for their accommodation and social care needs.

⁶⁴ See Commissioners for HMRC v Vermilion Holdings [2023] UK SC 37. At para 23 Lord Hodge said "The extent of the fiction created by a deeming provision is primarily a matter of construction of the statute in which it appears".

⁶³ In the opinion of the authors. This appears to be the inevitable conclusion as a matter of statutory construction but this conclusion is not supported by any existing High Court authority.

The staged test under Reg 21(7) of RSR Regs.

- 124. The language of Regulation 21(7) is slightly opaque and hence, in order for ICB decision makers to be confident that they are addressing the correct legal and factual issues, it may be sensible to approach this decision making in a series of stages, as follows⁶⁵:
 - (i) **Stage 1**: The decision maker must identify the "nursing or other health services required by that person". "Nursing services" must mean services which are required to be provided by a registered nurse and probably means the same as "nursing care" in s22(8) CA 2014. "Other health services" probably means services provided by other healthcare professionals such as doctors, occupational therapists, speech and language therapists and physiotherapists⁶⁶. These are the services that are identified in the assessments as being required by the person. The services that the ICB has to identify for this test may well be more extensive that the services presently being provided to the person if there is any element of unmet need;
 - (ii) Stage 2: Once the ICB has identified the "nursing or other health services required by that person", the next stage is to identify whether the person is being accommodated in "relevant premises" or not. The definitions in Reg 20 mean that relevant premises refers to premises which provide residential accommodation which is registered with the Care Quality Commission ("CQC"). It follows that all care homes, nursing homes and hospitals are "relevant premises". A person who lives in their own home or in supported living is not "accommodated in relevant premises" for the purposes of Reg 21(7). If a person is accommodated in relevant accommodation, the stage 3 test applies. If not, the stage 4 test applies;
 - (iii) **Stage 3**: Where a person is accommodated in relevant accommodation, the ICB has to reach a preliminary view whether the nursing or other health services required by that person are "more than incidental or ancillary to the

⁶⁵ The High Court sought to grapple with the effect of Reg 21(7) RSR Regs in *R (Gossip) v NHS Surrey Downs Clinical Commissioning Group* [2019] EWHC 3411 (Admin) but the judgment treats the matter at an unfortunately high degree of generality and does not engage with precisely what is required of a decision maker. It is a decision that ICBs may feel cautious about seeking to follow.

⁶⁶ This formulation is repeated in para 59 of the National Framework but is not expanded upon to explain what it means.

provision of accommodation which a social services authority is, or would be but for a person's means, under a duty to provide". It follows that the means of the person are irrelevant; the person must be treated as if they were entitled to social care support under the CA 2014 without making any financial contributions. The ICB then has to look at the type of nursing or other health services, their quantity and their quality of services and decide if these services can properly be described as "incidental or ancillary" to the provision of social care accommodation. The test asks the ICB to focus on what the ICB 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 ICB 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. This test is, in essence, a value judgement for health and social care professionals. There is clearly a spectrum where, at one end, a person has an occasional need for nursing or other health services, but where the vast majority of the person's needs are met by social care staff. At the other end of the spectrum is a case where health and social care staff are working in partnership, with a significant part of the person's overall needs being met by nurses or other healthcare professionals. In the latter case the level of input by nurses and other healthcare professionals into the overall care of the person would mean that the health level of input could not be described as being "incidental or ancillary". In summary the ICB decision maker needs to decide where each case is on this spectrum. If the answer is that the ICB's preliminary view is that the nursing and other health services are not more than incidental or ancillary to the provision of accommodation, the person will not have a primary health need under Reg 22(7) RSR Regs. Conversely, if the ICB decides that the nursing and other health services are more than incidental or ancillary to the provision of accommodation, the ICB proceeds to stage 5;

(iv) **Stage 4**: Where a person is not accommodated in relevant accommodation, the ICB has to reach a preliminary view whether the nursing or other health services required by the person are "of a nature"

beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide". This test looks at the nursing or other health services required by the person in their own home or in supported accommodation, and then requires the ICB to ask whether those services are "of a nature" that the local authority could be expected to provide. The answer to that question is straightforward if the person requires any level of services by a registered nurse⁶⁷. That could, for example, include wound dressing, the provision of complex medication or any other type of support which the assessment suggests is required to be carried out by a registered nurse. As local authorities are prohibited by s22(3) CA 2014 from providing or arranging such services, where a nurse is required the test will be met⁶⁸. If a person living at home does not require the services of a registered nurse but does require the services of physiotherapist, an occupational therapist or a speech and language therapist, the ICB needs to decide if these services are "of a nature" that a local authority could be expected to provide. If the ICB's preliminary view is that the nursing and other health services are not of a nature which beyond those a social services authority could be expected to provide, a decision can be reached that the person does not have a primary health need under Reg 22(7) RSR Regs. Conversely, if the ICB decides that the nursing and other health services are beyond those that a social services authority could be expected to provide, the ICB proceeds to stage 5.

(v) Stage 5: The final part of the test arises from the concluding words of Reg 22(7), namely that the ICB decision maker needs to make a final decision whether, "when considered in their totality" the nursing and other health services required by a person bring the case within one of the tests in Reg (22)(7)(a) or (b). There is no judicial guidance as to what the draftsman meant by the words "when considered in their totality" and no assistance is gained on this from the National Framework. However, the test clearly requires the ICB to look at the level of nursing and other health services required by a person in comparison to other services and ask whether, looking at the proportion of such services in the context of the total care needs of the person, the tests in in Reg (22)(7)(a) or (b) could be said to be

⁶⁷ As defined in s22(8) CA 2014.

⁶⁸ Even if the services are required on an intermittent basis.

met. There will inevitably be a measure of discretionary judgment in this exercise. It follows that, provided the ICB decision maker addresses the right question, a conclusion could only be overturned on rationality grounds. An example may be that a disabled person living at home will require the services of an NHS GP. That is plainly a service which is "of a nature" which a social services authority could not be expected to provide. Thus, as every disabled person living at home needs GP services, the test under reg 22(7)(b) could be said to be met. However, unless the person had a particularly acute or regular need for GP services, the ICB decision maker would be entitled to say that the disabled person's need for GP services "when considered in their totality" were such a small proportion of the overall needs of the person that the test under Reg 22(7)(b) was not met. The implication appears to be that, the greater the proportion of NHS services (i.e. non-local authority services) that a person, the more the decision will lean towards a conclusion that the person should be eligible for CHC.

Communicating a decision about CHC eligibility.

- 125. Once the decision has been made by the ICB, it needs to be communicated to everyone who has a legitimate interest in knowing the decision. Regulation 21(11) of the RSR Regs 2012 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)"
- 126. Unlike other provisions within the RSR Regs 2012, reg 21(11) does not specifically require the ICB to give reasons for its decision. However, the *National Framework* states:⁶⁹

⁶⁹At para 179.

"Once the eligibility decision is made by the ICB, the individual should be informed in writing as soon as possible (although this could be preceded by verbal confirmation where appropriate). This written confirmation should include:

- the decision on primary health need, and therefore whether or not the individual is eligible for NHS Continuing Healthcare;
- the reasons for the decision;
- a copy of the completed DST;
- details of who to contact if they wish to seek further clarification; and
- how to request a review of the eligibility decision"
- 127. The duty to have regard to the *National Framework* thus probably means that the ICB has a legal duty to give coherent reasons for its eligibility decision⁷⁰.

Recommended timescales for decision making.

128. The National Framework provides the following recommendations as to how long an ICB should take to complete the CHC eligibility decision making process:

"Timeframe for decision making

182. It is expected that ICBs will normally respond to MDT recommendations within 48 hours (two working days), and that the overall assessment and eligibility decision- making process should, in most cases, not exceed 28 calendar days from the date that the ICB receives the positive Checklist (or, where a Checklist is not used, other notice of potential eligibility) to the eligibility decision being made.

183. In the minority of cases where an assessment of eligibility is being carried out in an acute hospital setting, the process should take far fewer than 28 calendar days if an individual is otherwise ready for discharge.

184. When there are valid and unavoidable reasons for the process taking longer, timescales should be clearly communicated to the person and

⁷⁰ Possible save for very rare cases where the ICB would have particular reasons for not doing so, such as where the disclosure of reasons for a decision to relatives may prejudice the position of the patient.

(where appropriate) their representative(s). An example of this might occur where additional work is required to ensure that the DST and supporting evidence submitted to the ICB accurately reflect the full extent of an individual's needs. It should also be noted that the 28 calendar day timescale does not apply to children and young people in transition to adult services (refer to paragraph 368)"

129. In practice, many ICBs take far longer than the recommended 28 days and some do not have processes in place which, if followed, could result in decisions being made in accordance with the above guidance. In practice there is little a patient of family member can do (other than raising a complaint) where an ICB fails to have systems in place to make CHC decisions within the recommended 28-day timetable. However, if a positive CHC decision is made more than 28 days after the ICB ought to have commenced the assessment process, the guidance makes it clear that the ICB should generally backdate the effect of the decision to 28 days after the decision ought to have been made and should reimburse the patient (or the local authority) for care costs incurred in any period of delay⁷¹.

The Fast Track Pathway decision-making processes

- 130. The CHC processes recognise that there will be patients whose needs are so pressing 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 regulation 21(8) to (10) of the RSR Regs 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, and that clinician has completed a Fast Track Pathway Tool stating reasons for the decision.

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⁷¹ See Annex E to the National Framework, as discussed ay para XX below.

- (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-funded nursing 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"
- 131. 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 ICB; and
 - c) Once the decision is made by an appropriate clinician that the statutory test is met, the ICB 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 ICB: see by analogy *R (Crudace) v Northumbria Police Authority*.⁷²
- 132. 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"

⁷²[2012] EWHC 112 (Admin) at paras 63-70.

133. The 'Fast Track Pathway Tool' is published by the Department of Health and Social Care.⁷³ The purpose is explained at paragraph 13:

"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 CCG⁷⁴ 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"

This approach is very largely replicated at paragraphs 240 to 259 of the *National Framework*.

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

⁷³See https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care.

⁷⁴ References to a CCG should now be read as references to an ICB.

"ICB responsibilities upon receiving a completed Fast Track Pathway Tool

260. In order to comply with Standing Rules an ICB must accept and immediately action a Fast Track Pathway Tool where the Tool has been properly completed.

261. Exceptionally, there may be circumstances where ICBs receive a completed Tool which appears to show that the individual's condition is not related to the above criteria at all. For example, if a completed Fast Track Pathway Tool states that the person has mental health needs and challenging behaviour but makes no reference to them having a rapidly deteriorating condition which may be entering a terminal phase. In these circumstances, the ICB should urgently ask the relevant clinician to clarify the nature of the person's needs and the reason for the use of the Fast Track Pathway Tool. Where it then becomes clear that the use of the Fast Track Pathway Tool was not appropriate, the clinician should be asked to submit a completed Checklist (if required) for assessment of eligibility through the process outlined in this National Framework.

262. Action should be taken urgently to agree and commission the care package. ICBs should have processes in place to enable such care packages to be commissioned quickly. Given the nature of the needs, this time period should not usually exceed 48 hours from receipt of the completed Fast Track Pathway Tool. ICBs should ensure that they have commissioned sufficient capacity in the care system to ensure that delays in the delivery of care packages are minimal. 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 Pathway Tool are resolved.

263. ICBs should ensure that robust systems are in place to audit and monitor use of the tool and raise any specific concerns with clinicians, teams and organisations, bearing in mind the importance of the Tool being used appropriately and only for the genuine purpose for which it is intended. ICBs should consider how the use of the standard NHS contract can support this.

Such concerns should be treated as a separate matter from the task of arranging for service provision in the individual case"

135. Although the initial decision maker to award CHC under the Fast Track is a clinician, the ICB remains the relevant decision maker to determine whether any CHC package should be continued. The National Framework explains that the ICB should review all awards under the Fast Track as follows:

"Reviews of Fast Track

- 264. The aim of the Fast Track Pathway Tool is to ensure quick determination of eligibility for NHS Continuing Healthcare and commissioning an appropriate care package.
- 265. Once this has happened, it will be important to review an individual's care needs and the effectiveness of the care arrangements. In doing this, there may be certain situations where the needs indicate that it is appropriate to review eligibility for NHS Continuing Healthcare. ICBs should make any decisions about reviewing eligibility in Fast Track cases with sensitivity.
- 266. Where an individual who is receiving services from use of the Fast Track Pathway Tool is expected to die in the very near future, the ICB should continue to take responsibility for the care package until the end of their life.
- 267. ICBs should monitor care packages to consider when and whether a reassessment of eligibility is appropriate. Where it is apparent that the individual is rapidly deteriorating and may be entering a terminal phase and the original eligibility decision was appropriate, it is unlikely that a review of eligibility will be necessary.
- 268. No individual identified through the Fast Track Pathway Tool who is eligible for NHS Continuing Healthcare should have this funding removed without their eligibility being re-considered through the completion of a DST by a multidisciplinary team (MDT), including this MDT making a recommendation on eligibility for NHS Continuing Healthcare.

269. The individual affected should be notified in writing of any proposed change in funding responsibility. They should be given details of their right to request a review of the decision. Such communications should be conducted in a sensitive, timely and person-centred manner"

136. 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.

Part D: NHS-funded nursing care.

- 137. Disabled people who live outside hospitals often need a combination of support from social care workers who are not formally medically qualified and from registered nurses. If the person lives at home, nursing support can be provided by a district nurse employed by the local NHS community trust. However, NHS employed district nurses generally do not provide services to residents of nursing homes, who employ their own nurses. However, any care for a care home resident who needs an element of nursing care will generally not be permitted to be funded by a local authority because of the prohibition on local authorities funding nursing care in s22 CA 2014 as explained above⁷⁵.
- 138. NHS-funded Nursing Care exists to fill this gap by providing ICB funding to a care home to meet the cost of providing nursing support for a resident who is assessed as eligible for NHS-funded Nursing Care.
- 139. NHS-funded nursing care is covered by Part 6 of the RSR Regs 2012. 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"

⁷⁵ There may be cases where nursing care can be funded by a local authority despite 22(4) CA 2014 if the conditions in that section are met, despite the prohibitions in sections 22(1) to (3).

- 140. Regulation 28 of the RSR Regs 2012 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"

This regulation makes it clear that NHS-funded nursing care involves the ICB making a contribution towards the overall cost of care home fees for patient who (a) is not eligible for fully funded CHC and (b) needs a measure of nursing support⁷⁶. Guidance on determining the need for NHS-funded nursing care is provided at paras 270 to 275 of the National Framework.⁷⁷

- 141. Patients cannot qualify both for CHC and NHS-funded nursing care: see reg 28(3) of RSR Regs. 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 ICB to commission a local provider to provide this service.
- 142. Regulation 28 imposes a duty on the ICB (or possibly NHS England) to carry out an assessment of the patient's need for nursing care. However, reg 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.
- 143. The standard level of payment of FNC from 1 April 2023 is £219.71 per week.

 Before 1 October 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 1 October 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 1 October 2007 and was awarded the high

⁷⁶ The level of nursing support must not be "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, applying the tests under reg 22(7), the patient would be eligible for CHC.

⁷⁷See National Framework p86.

band, NHS-funded nursing care continues to be paid at the higher rate, which from 1 April 2023 is £302.25 per week.

144. Patients are entitled ⁷⁸ to continue on the standard FNC rate unless:

- 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 of £112.00 a week; or
- d) the patient becomes entitled to CHC; or
- e) the patient dies.

Part E: Reviews, appeals and complaints by patients or relatives who disagree with CHC eligibility decisions.

- 145. The RSR Regs provide for a multi-level procedure for patients and their relatives to be able to follow where there is dissatisfaction with the CHC eligibility decision.

 The options available are in summary:
 - a) An application for a review by the ICB;
 - b) An appeal to an NHS England panel;
 - c) A formal complaint against either the ICB or NHS England under the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009;
 - d) A complaint to the PHSO; and
 - e) Judicial Review.

Stage 1: ICB Reviews: Local resolution.

146. Regulation 21(11) provides that the patient must be told that he or she can seek a review of the decision. The *National Framework* explains how the ICB should

⁷⁸The entitlement is set out on the NHS Choice website at www.nhs.uk/chq/Pages/what-is-nhs-funded-nursing-care.aspx.

respond if the patient or their family asks for a review of a CHC eligibility decision. It states at paras 214 to 215:

"Local resolution

- 214. Where an individual or their representative asks the ICB to review the eligibility decision, this should be addressed through the local resolution procedure, which is normally expected to resolve the matter. ICBs should deal with requests for review in a timely manner. For guidance on this issue please refer to NHS England website.
- 215. All ICBs must have an NHS Continuing Healthcare local resolution process. They should therefore develop, deliver and publish a local resolution process that is fair, transparent, includes timescales and takes account of the following guidelines:
- (a) There should be an attempt to resolve any concerns initially through an informal two-way meaningful discussion between the ICB representative and the individual and/or their representative. There should be a written summary of this for both parties. The discussion should be an opportunity for the individual or their representative to receive clarification of anything they have not understood. The ICB should explain how it has arrived at the decision regarding eligibility, including reference to the completed DST and primary health need assessment. Where required this should also be an opportunity for the individual or their representative to provide any further information that had not been considered.
- (b) Where a formal meeting involving the individual and/or their representative is required, this should involve someone with the authority to decide next steps on behalf of the ICB (e.g. to request further reports or seek further clarification/reconsideration by the MDT). The individual should be able to put forward the reasons why they remain dissatisfied with the ICB's decision. There should be a full written record of the formal meeting for both parties. The ICB will agree next steps with the individual or their representative.

- (c) Following the formal meeting and outcome of the next steps, the ICB will either uphold or change the original eligibility decision.
- (d) A key principle of the local resolution process is that, as far as possible, if the ICB does not change the original decision, the individual or their representative has had a clear and comprehensive explanation of the rationale for the ICB decision.
- (e) Where individuals wish to move straight to a formal meeting this should be considered. ICBs should use every opportunity to learn from these meetings, and should consider how they share their learning with other ICBs.
- (f) ICBs may choose to prioritise cases for individuals currently in receipt of care"
- 147. The above guidance makes it clear that the purpose of a review process is not just to allow the ICB an opportunity to explain the decision to the patient of the family. It should also be an opportunity for the patient to explain why he or she considers the decision was erroneous and for the ICB to reflect on whether it wishes to change the decision. That is only possible in practice if the review is undertaken by staff who were not involved in the original decision, or the ICB staff will be marking their own homework.

Stage 2: NHS England Independent Review Panel process.

148. Reg 23(1) RSR Regs requires NHS England to set up an Independent Review Panel ("IRP") for CHC decisions. Reg 23(3) then provides:

"Where a person, or someone lawfully acting on a person's behalf—

(a) is dissatisfied with—

- (i) the procedure followed by a relevant body in reaching a decision as to that person's eligibility for NHS Continuing Healthcare pursuant to regulation 21(5), or
- (ii) the primary health need decision by a relevant body pursuant to regulation 21(5)(b); and

(b) the person has—

- (i) used the resolution procedure of the relevant body in question, but that has not resolved the matter, or
- (ii) not used that resolution procedure and NHS England is satisfied that requiring the person to do so would cause undue delay, that person may apply in writing to NHS England for a review of that decision"
- 149. Where an application is made under Reg 23(3), NHS England has a discretion to decide whether to refer the case for a panel to review⁷⁹. Once a referral is made, the NHS England panel is under a duty to 'review' the decision: see reg 23(5) of the RSR Regs. NHS England has published a Guide to the Review process⁸⁰ which states:

"You can only introduce new evidence for the IR process if it would be reasonable to have expected the ICB to have obtained and/or considered this evidence when conducting your assessment and making its decision, but it failed to do so.

This is your final opportunity to provide further information and you cannot introduce additional information at a later stage in the process"

150. Annex D to the National Framework⁸¹ sets out details of the recommended IRP process. In contrast to the position of the patient, the panel can and should consider whether to seek new evidence. Annex D states at para 18:

"The IRP will require access to independent clinical advice, which should take account of the range of medical, nursing and therapy needs involved in each case. Such arrangements should avoid any obvious conflicts of interest

⁷⁹ But it is not obliged to do so and could, for example in a case with a vexatious complainant, decide not to refer the case for a panel review. Para 11 of Annex D states "NHS England does have the right to decide in any individual case not to convene an IRP. It is expected that such a decision will be confined to those cases where the individual falls well outside the eligibility criteria, or where the case is very clearly not appropriate for the IRP to consider".

⁸⁰ See https://www.england.nhs.uk/wp-content/uploads/2020/03/nhs-continuing-healthcare-independent-review-process.pdf

⁸¹ See page 173 of https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf

between the individual clinician(s) giving the advice and the organisation(s) from which the individual has been receiving care. The chair of the relevant IRP should consider in advance of the hearing whether, bearing in mind the nature of the case, the evidence supplied and the role of the clinical adviser set out in paragraph 19 below, there is a need for the panel to access independent clinical advice, and whether this should be in the form of attendance at the hearing or of the clinician supplying written advice"

151. Where a review meeting is held, NHS England's guidance states that it is usually held by way of an online meeting and the patient or their representative is entitled to attend. There are three potential outcomes of a review process, namely (a) it can affirm the ICB negative CHC decision, it can reverse the decision and recommend the ICB to find that the patient is eligible for CHC or (c) it can send the case back to the ICB for reconsideration. The Guidance states:

"The only basis on which the IR panel can recommend you are eligible is if it decides you have a 'primary health need' according to the principles set out in the National Framework.

In certain circumstances where we believe procedural problems prevented the ICB making a robust decision, your case may be referred back to the ICB. If your case is sent back to the ICB for a full re-assessment, you will be entitled to apply for an additional IR of that full re-assessment if you disagree with the outcome"

152. Regulation 23(8) and (9) provide that the ICB 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 ICB made of the patient's needs or has come to an irrational conclusion.

Stage 3: A formal complaint against either the ICB or NHS England under the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009.

153. A patient or their family members who remain dissatisfied with a negative CHC decision have the right to make a complaint about the decision and/or the process

leading to the decision under the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009 ("the Complaints Regs").

Stage 4: A complaint to the PHSO.

154. If a patient or their family members who remain dissatisfied with the way that their complaint about a negative CHC decision has been handled, a complaint can be made to the PHSO⁸².

Judicial Review.

155. There have been relatively few judicial reviews relating to a challenge to a failure by an NHS commissioning body to determine that a person is eligible for CHC. A successful challenge was made in a Children's CHC case in *R (JP) v NHS Croydon Clinical Commissioning Group* [2020] EWHC 1470 (Admin) and unsuccessful challenges were made in both, *R (Whapples) v Birmingham Crosscity Clinical Commissioning Group & Anor* [2015] EWCA Civ 435 and in *R (Gossip) v NHS Surrey Downs Clinical Commissioning Group* [2019] EWHC 3411 (Admin).

Disputes between ICBs and local authorities over CHC eligibility.

156. Unlike patients or their relatives, local authorities are unable to appeal to NHS England panels. Disputes between local authorities and ICBs need to be resolved using dispute resolution procedures agreed between the two public bodies.

Regulation 22(2) of the RSR Regs 2012 provides:

"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"

⁸² See https://www.ombudsman.org.uk/

- 157. Thus, there is a statutory duty on each ICB 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 ICB is under a statutory duty to use the procedure to resolve the disagreement.
- 158. The National Framework provides at paras 232 to 235:83
 - "232. Nevertheless, there may be instances where disputes arise. A fundamental principle is for ICBs and local authorities to minimise the need to invoke formal inter-agency dispute resolution procedures by, for example:
 - (a) all parties following the guidance set out in this National Framework;
 - (b) agreeing and following local protocols and/or processes which make clear how the ICB discharges its duty to consult with the local authority (refer to paragraph 22) and how the local authority fulfils its role as an important partner in the NHS Continuing Healthcare process, (refer to paragraphs 26-31);
 - (c) developing a culture of genuine partnership working in all aspects of NHS Continuing Healthcare;
 - (d) ensuring that eligibility decisions are based on thorough, accurate and evidence-based assessments of the individuals' needs;
 - (e) always keeping the individual at the centre of the process and ensuring a person-centred approach to decision-making;
 - (f) always attempting to resolve inter-agency disagreements at an early and preferably informal stage;

⁸³At para 159.

- (g) dealing with genuine disagreements between practitioners in a professional manner without drawing the individual concerned into the debate in order to gain support for one professional's position or the other;
- (h) ensuring practitioners in health and social care receive high-quality joint training (i.e. health and social care) which gives consistent messages about the correct application of the National Framework.

Individuals must never be left without appropriate support while disputes between statutory bodies about funding responsibilities are resolved"

- 233. ICBs and local authorities in each local area must agree a local disputes resolution process to resolve cases where there is a dispute between them about:
 - a decision as to eligibility for NHS Continuing Healthcare, or
 - where an individual is not eligible for NHS Continuing Healthcare, the contribution of an ICB or local authority to a joint package of care for that person, or
 - the operation of refunds guidance (see Annex E).
- 234. When developing and agreeing local inter-agency disagreement and dispute resolution protocols, ICBs and local authorities should ensure that they encompass the following elements:
 - A brief summary of principles including a commitment to work in partnership and in a person-centred way.
 - The ICB duty to consult with the local authority (refer to paragraph 22) and the expectation that the local authority works jointly with the ICB in carrying out the NHS Continuing Healthcare process (refer to paragraphs 26-31). This should include arrangements for situations where the local authority has not been involved in the MDT and in formulating the recommendation.
 - An 'informal' stage at operational level whereby disagreements
 regarding the correct eligibility recommendation can be resolved this
 might, for example, involve consultation with relevant managers
 immediately following the MDT meeting to see whether agreement can

- be reached. This stage might include seeking further information/clarification on the facts of the case or on the correct interpretation of the National Framework.
- A formal stage of resolving disagreements regarding eligibility recommendations involving managers and/or practitioners who have delegated authority to attempt resolution of the disagreement and can make eligibility decisions. This stage could involve referral to an interagency NHS Continuing Healthcare panel.
- If the dispute remains unresolved, the dispute resolution agreement may provide further stages of escalation to more senior managers within the respective organisations.
- A final stage involving independent arbitration. This stage should only be invoked as a last resort and should rarely, if ever, be required. It can only be triggered by senior managers within the respective organisations who must agree how the independent arbitration is to be sourced, organised and funded.
- Clear timelines for each stage.
- Agreement as to how the placement and/or package for the individual
 is to be funded pending the outcome of dispute resolution and
 arrangements for reimbursement to the agencies involved once the
 dispute is resolved. Individuals must never be left without appropriate
 support whilst disputes between statutory bodies about funding
 responsibility are resolved.
- Arrangements to keep the individual and/or their representative informed throughout the dispute resolution process.
- Arrangements in the event of an individual requesting a review of the eligibility decision made by the ICB.

235. It should be remembered that decisions regarding eligibility for NHS Continuing Healthcare are the responsibility of the ICB, who may choose to make their decision before an inter-agency disagreement has been resolved. In such cases it is possible that the formal dispute resolution process will have to be concluded after the individual has been given a decision by the ICB"

159. Annex F to the *National Framework* sets out best practice guide for what to include when drawing up and updating local protocols and procedures regarding NHS Continuing Healthcare. The final stage, independent arbitration can be undertaken by instructing someone (such as a barrister experienced in CHC matters) to act as an arbitrator. However, as the Court of Appeal made clear in *R* (*St Helens Borough Council*) *v Manchester Primary Care Trust and another*,⁸⁴ 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.

Part F: Funding reimbursement after a CHC decision or where the ICB failed to take a positive CHC decision when it ought to have done so.

- 160. A person only becomes eligible for NHS continuing healthcare once a decision on eligibility has been made by an ICB, informed by a completed Decision Support Tool. Funding becomes available to a person who is assessed under the Fast Track Pathway Tool as soon as a positive decision is made by the approved clinician. Prior to a positive eligibility decision being made, any existing arrangements for the provision and funding of care should continue, unless there is an urgent need for adjustment. If, at the time of referral for a CHC assessment, the individual is already receiving ongoing care and support funded by the patient, family an ICB, or a local authority, those arrangements should continue until the ICB makes its decision on CHC eligibility, subject to any urgent adjustments needed to meet the changed needs of the individual⁸⁵.
- 161. Once the CHC assessment process commences, the National Framework suggests that it should be completed with a CHC eligibility decision taken with 28 days. However, there are a number of situations in which a patient, family members or a local authority may incur care costs during a period prior to CHC decisions being made where reimbursement could be sought. These situations are broadly as follows:
 - (i) Where the ICB either fails to start the assessment process despite being on notice that the person may be eligible for CHC or delays doing so that a CHC decision is made later than it ought to have been;

^{84[2008]} EWCA Civ 931, (2008) 11 CCLR 774.

⁸⁵ See National Framework at paras 2 and 3 of Annex E.

- (ii) Where the ICB takes longer than 28 days to complete the MDT and decision-making process, absent individual factors in the case which could justify a longer decision making period;
- (iii) Where the ICB makes an initial negative decision but later accepts that the person is eligible for CHC as a result of an ICB review, an IRP recommendation, an NHS complaint or where the initial negative decision is quashed by the Court.
- 162. The discharge of the ICB's decision making duties under Reg 21 RSR Regs is the discharge of a public function but probably does not give rise to a private law duty of care to a person who may have an entitlement. Thus, in principle, there is no private law action in damages that a person could bring arising out of any delay or failure by the ICB to discharge its legal obligations. However, a failure by the ICB to discharge its legal duties to a person who was eligible for CHC could give rise to a claim in restitution by anyone who was required to pay care costs as a result of that public law failure by the ICB: see *Surrey County Council v NHS Lincolnshire Clinical Commissioning Group* [2020] EWHC 3550 (QB)⁸⁶.
- 163. Annex E of the National Framework recommends that, where the ICB has delayed in making an assessment, it should refund costs incurred by the patient or by a local authority from the 29th day after the date when the ICB ought to have made a decision. The start of this period is described as follows:

"Decision-making on eligibility for NHS Continuing Healthcare should, in most cases, take no longer than 28 calendar days from the ICB (or organisation acting on behalf of the ICB) being notified of the need for assessment of eligibility for NHS Continuing Healthcare e.g. an appropriately completed positive Checklist, or other notification that an assessment of eligibility is required"

164. As a matter of law, an ICB is "notified of the need for assessment of eligibility" when it has sufficient information to know that a person "may" be eligible for CHC. As explained above, this is a low threshold. However, the duty to assess only arises when the relevant information is known by the ICB, not just by clinicians

⁸⁶ This case has given rise to considerable academic and judicial comment, not all of which is positive but overall the principles appear to be supported. See for example the speech by Foxton J at https://www.bailii.org/uk/other/speeches/2021/M1EUP.html

who are treating the person. The start date for this period should thus be focused on when information about the person was communicated by anyone to a representative of the ICB.

- 165. The Guidance recommends payments should be made to cover periods for delay as follows:
 - "12. Where unreasonable delay has occurred and it is an LA that has funded services during the interim period, the ICB should refund the local authority the costs of the care package that it has incurred during the period of unreasonable delay. The ICB can use its powers under section 256 of the NHS Act to make such payments. The amount to be refunded to the local authority should be based on the gross cost of the services provided. Where an individual has been required to make financial contributions to the local authority as a result of an assessment of their resources under the Care Act 2014, the above approach should be adopted rather than the ICB refunding such contributions directly to the individual as the refund of contributions is a matter between the local authority and the individual. Where an ICB makes a gross cost refund, the local authority should refund any financial contributions made to it by the individual in the light of the fact that it has been refunded on a gross basis, including interest.
 - 13. Where an ICB has unreasonably delayed reaching its decision on eligibility for NHS Continuing Healthcare, and the individual has arranged and paid for services directly during the interim period, the ICB should make an ex-gratia payment in respect of the period of unreasonable delay"
- obligation (and hence there is no private law right to make the payment) but instead the ICB would be using its general powers to make an *ex gratia* payment. It follows that any refusal by an ICB to make a requested payment could only be challenged legally by way of judicial review and not directly in a private law action in the High Court (although following *Surrey County Council v NHS Lincolnshire Clinical Commissioning Group* payment could be sought by way of a restitution claim).

Retrospective reimbursement claims.

- 167. For several years, following pressure from a series of decisions of the PHSO, NHS commissioning bodies were advised to consider claims for reimbursement of care costs (usually care home fees) from relatives who argued that, in summary, a person should have been awarded CHC and thus the care home fees should have been paid by the NHS and not by the patient or by relatives. A private law action to seek to recover those fees was rejected by the High Court as an abuse of process in *Jones v Powys Local Health Board & Anor* [2008] EWHC 2562 (Admin) on the grounds that any challenge to the discharge of public law decision making by an NHS body could only be brought by judicial review and not by way of a damages claim. Nonetheless, thousands of claims were made, each case was examined and substantial *ex gratia* payments were made to families where the NHS commissioning body decided that the patient ought to have been awarded CHC.
- 168. As a result of guidance produced by the DHSC⁸⁷, retrospective CHC claims for previously unassessed periods of care should not generally be entertained by ICBs for periods prior to April 2012. The Guidance provides that requests should be considered where the following criteria are met:

"A request for a PUPoC⁸⁸ assessment refers to a request for an ICB to consider NHS CHC eligibility where the ICB had responsibility for an individual, for a specific past period of care, where:

- there was no consideration of NHS CHC eligibility by the relevant ICB for that individual during the past period of such care
- that individual had funded that past period of care in full or in part
- there is appropriate, objective evidence that the individual should have been considered for eligibility for NHS CHC in accordance with <u>The</u> <u>National Health Service Commissioning Board and Clinical</u> <u>Commissioning Groups (Responsibilities and Standing Rules)</u> <u>Regulations 2012</u> (as amended) and the national framework"
- 169. The Guidance makes it clear that, if the CCG carried out a CHC decision making process at the relevant time (which was then not successfully challenged on

 $^{{}^{87}\,}See \,\,\underline{\text{https://www.gov.uk/government/publications/continuing-healthcare-previously-unassessed-periods-of-care/dealing-with-requests-for-assessments-of-previously-unassessed-periods-of-care-from-1-april-2012}$

⁸⁸ PUPoC stands for "Previously Unassessed Period of Care"

appeal), the ICB is not required to re-open the case. Thus claims can only be made where the patient (or relatives) are able to show that (a) the patient's circumstances were drawn to the attention of the relevant CCG, (b) those circumstances were sufficient to have triggered a duty on the CCG to carry out an assessment and (c) no checklist or MDT assessment was carried out by the CCG and thus no decision was made as to whether the patient was eligible for CHC. It follows that a patient whose clinical circumstances alone may have been sufficient to justify a positive CHC eligibility decision may nonetheless not be eligible for a retrospective payment unless there is evidence to show that those circumstances were drawn to the attention of the CCG.

- 170. If, as an alternative to the discretionary process set out above, the patient or family pursue a claim in court, the claim could only be brought as a claim to restitution and that claim would be subject to a 6 year time limit under the Limitation Act 1980⁸⁹. Hence, absent fraud or deliberate concealment, ICBs should not now have to face any retrospective CHC legal claims for any period prior more than 6 years before the claim is made.
- 171. Where the ICB changes its decision about CHC eligibility as a result of an ICB review, an IRP recommendation, an NHS complaint or where the initial negative decision is quashed by the Court and, in any case, later accepts that the person is eligible for CHC, the above guidance recommends an *ex-gratia* payment should be made to reimburse either the local authority or the patient (or relatives) for any care costs incurred in the period of delay. There can be difficult decisions for ICBs about reimbursement where a patient has a deteriorating condition and, eligibility is established on an IRP review on the basis of the patient's presenting condition at that date⁹⁰. In such a case an ICB may have to make a balanced decision as to whether to offer a full or only partial reimbursement. As these are ex-gratia payments, the ICB will have a considerable degree of discretion to award such a reimbursement amount as it considers appropriate.

Part G: Hospital Discharge and CHC assessments.

⁸⁹ As Thornton J found in Surrey County Council v NHS Lincolnshire Clinical Commissioning Group.

⁹⁰ Final IRP hearings can be as much as 12 months after the initial ICB decision and thus the clinical picture may well have changed in that period.

172. There can be considerable difficulties if the patient is ready 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 while the review procedures are being carried out. There is strong clinical evidence supporting the D2A model, with assessments taking place after hospital discharge. Whilst there is a tension between that approach and the wording of the RSR Regs which is examined above⁹¹, CHC assessments should not hold up hospital discharges.

Part H: What package of NHS funded services should be provided to an NHS CHC eligible patient?

173. An ICB has two different types of decision to make:

- (i) Is the patient eligible for CHC?
- (ii) If the patient does qualify, what package of support should be provided by the ICB and others including the local authority to support the patient.
- 174. Once the ICB has made the decision that the patient is eligible for CHC, the ICB comes under a duty to offer an appropriate package of services to meet all of the patient's eligible needs for medical services, social care services and accommodation (where that is part of the need). This duty is explained in paras 185 to 186 of the *National Framework* which provide:

"Care planning and delivery

185. Where an individual is eligible for NHS Continuing Healthcare, the ICB is responsible for care planning, commissioning services, and for case management. It is the responsibility of the ICB 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 The services commissioned must include ongoing case management for all those eligible for NHS Continuing Healthcare, including review and/or reassessment of the individual's needs.

186. ICBs should operate a person-centred approach to all aspects of NHS Continuing Healthcare, using models that maximise personalisation and

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⁹¹ See para XX.

individual control and that reflect the individual's preferences, as far as possible, including when delivering NHS Continuing Healthcare through a Personal Health Budget, where this is appropriate (refer to paragraphs 320-324)"

175. The *National Framework* explains that the ICB becomes responsible for case management for anyone eligible for CHC and recommends that the ICB appoint a named case manager for each eligible person⁹². Further guidance on care planning, commissioning and provision is set out at paras 191 to 200. However, notwithstanding the general words in the National Framework, 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. The services to be provided as part of a CHC package are services under s3 NHSA 2006 and are thus governed by the same approach to the need to balance the needs of one person against the needs of others as apply to every other NHS service.

Legal issues arising from care planning and delivery.

- 176. It is beyond the scope of this guide to describe the detailed steps that ICBs have to take in order to undertake their duties to persons who are eligible for CHC. These steps are set out in the National Framework and are not repeated here. However, the process of care planning and delivery can give rise to the following areas of legal challenge:
 - (i) Accommodation: When is an ICB obliged to provide accommodation as part of the package of services for a person eligible for CHC:
 - (ii) When is the ICB obliged to fund aids and adaptations in a person's own home?
 - (iii) When can an ICB insist on discharging its duties by providing a package of care in a care home as opposed to providing a bespoke care package in the person's own home?
 - (iv) When and/or how can a patient or their family contribute towards the cost of a CHC package so as to maintain a patient in the location of their choice?
 - (v) CHC patients who are admitted to hospitals as in-patients.
 - (vi) Legal issues arising out of providing a care package in a patient's home.

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⁹² See para 187.

When is an ICB required to offer accommodation as part of a CHC package?

177. The National Framework provides at page 10⁹³ that, where a person is eligible for CHC:

"the NHS is responsible for providing for all of that individual's assessed health and associated social care needs, including accommodation, if that is part of the overall need"

178. It is trite to say that everyone needs some form of accommodation in which to live. However, the NHS is not obliged to meet the accommodation costs of every person who is eligible for CHC. This issue was examined in detail by the Court of Appeal in *R (Whapples) v Birmingham Crosscity Clinical Commissioning Group & Anor* [2015] EWCA Civ 435. Having analysed the different parts of the National Framework, the Judges decided that an NHS commissioning body had a considerable discretion to decide whether someone who was living in their own home had a "need" for accommodation to be provided as part of a CHC package. In that case, Ms Whapples needed to move from her own flat but had refused to engage with a housing association that was prepared to provide her with suitable housing. The Court was not prepared to say that the duty to provide accommodation where this is part of a person's needs extended to a situation where a person was refusing other options for appropriate accommodation. Burnett LJ said at para 30:

"To the extent that ordinary residential accommodation is needed which the patient cannot arrange and fund for himself, the distribution of responsibility places such accommodation needs upon local authorities, rather than the NHS. If the patient can provide his own accommodation, funded privately or with the assistance of benefits, he is expected to do so"

179. Applying this approach, Burnett LJ said:

"She has declined offers of assistance in seeking alternative accommodation unless the offer includes an acceptance on the part of the

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⁹³ And repeated at para 55.

CCG to provide it or fund it. In the meantime, and contrary to her own best interests, she has continued to decline any assistance with her care. As the judge observed, in these circumstances the CCG was entitled to conclude either that the appellant has no reasonable requirement for accommodation provided or funded by the NHS, or that it is not necessary to provide it (or both). There is every reason to suppose that, with the appellant's cooperation, suitable alternative accommodation will be found for her"

- 180. That language rooted the NHS commissioning body's duty firmly to the words of s3(1) NHSA 2006, namely that the ICB is entitled to ask itself if a patient has a "requirement" for NHS funded accommodation. Hence, in practice, that test will rarely be met outside of accommodation in a care home or other setting where the care support is closely linked to the provision of accommodation.
- 181. The National Framework provides the following guidance at para 315 about what costs the ICB should meet if a person is supported in their own home:

"Where an individual is eligible for NHS Continuing Healthcare and chooses to live in their own home, the ICB is financially responsible for meeting all assessed health and associated social care needs. This could include: equipment provision (refer to Practice Guidance note 56), routine and incontinence laundry, daily domestic tasks such as food preparation, shopping, washing up, bed-making and support to access community facilities, etc. (including additional support needs for the individual whilst the carer has a break). However, the NHS is not responsible for funding rent, food and normal utility bills"

When is the ICB obliged to fund aids and adaptations in a person's own home?

182. Where an individual is eligible for CHC, it may well be that the provision of equipment and/or adaptations is identified as being an appropriate way to meet some of these needs. There is detailed guidance on this in PG 56⁹⁴ which, in summary, explores the possibility of the ICB helping the person to make an application for a Disabled Facilities Grant ("**DFG**") from the local authority under the Housing Grants, Construction and Regeneration Act 1996 but also recognises that (a) such grants are means tested and the person may not be eligible for the

⁹⁴ See page 160 of the National Framework.

grant and (b) the local authority would be entitled to take the view that the person did not have a need for the grant because the aids and adaptations were required to be provided by the ICB. The Guidance states⁹⁵:

"ICBs are reminded that in such circumstances they must give consideration to the option of funding the adaptation if this is a cost-effective solution"

183. The Guidance thus explains that, if the person has a need for aids and adaptations, the costs may well have to be met by the ICB even though these are capital items. The Guidance provides at PG56.5:

ICBs should be aware of their responsibilities and powers to meet housingrelated needs for those eligible for NHS Continuing Healthcare:

- (a) ICBs have a general responsibility under section 3(1)(i) 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) NHS England 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) ICBs 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) ICBs also have a more general power to make payments to local authorities towards expenditure incurred by the local authority in connection with the performance of any local authority 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.

⁹⁵ See para 56.4 of Practice Guidance

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

When can an ICB insist on discharging its duties by providing a package of care in a care home as opposed to providing a bespoke care package in the person's own home?

- 184. One of the most difficult areas of practice can be managing the tension between an individual's desire to stay in their own home with a bespoke set of carers to support the person in circumstances where providing that service to an individual costs far more than a care home placement where the care costs are shared between the individuals in the care home. The National Framework emphasises that the person must "be provided with information or signposting to enable informed choices, and supported to make their own decisions" concerning the type of care package on offer the person⁹⁶. However, there may well be packages where the cost of paying staff to work exclusively for a single person is far higher than the cost of an appropriate care home placement.
- 185. The National Framework explains the level of discretion open to an ICB at PG45 as follows:

"PG 45 Can ICBs take comparative costs and value for money into account when determining the model of support to be provided to an individual?

- 45.1 Yes, subject to the following guidance and the guidance set out in paragraphs 298-309 of the National Framework. In some situations a model of support preferred by the individual will be more expensive than other options. ICBs 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:
- 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

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⁹⁶ See para 188 of the National Framework.

the specific needs in the case and not on an assumed standard care home cost.

• 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. ICBs should consider whether models such as assistive technology could meet some of these needs. Where individuals are assessed as requiring nursing care, ICBs 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. ICBs should not make assumptions about any individual, group or community being available to care for family members.

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 Practice Guidance note 46)"

- 186. The reference to the Gunter case is a reference to R (*Gunter*) v South Western Staffordshire Primary Care Trust [2005] EWHC 1894 (Admin)⁹⁷. In that case the claimant alleged the PCT acted unlawfully because it was not prepared to create an "Independent User Trust⁹⁸" which would have allowed her parents to buy care for their daughter and thus avoid the need for her to go into care. Whilst the Judge accepted that it would be intra vires for the PCT to set up such an arrangement, he also said at para 28:
 - "... cost is an important consideration and it may turn out that the IUT route is not satisfactory or does not provide the sort of saving which can to a sufficient extent bridge the gap between care at home and residential care"

⁹⁷ See https://www.bailii.org/ew/cases/EWHC/Admin/2005/1894.html

⁹⁸ This case occurred prior to NHS services being funded by Personal Health Budgets.

187. Thus, the Gunther case provides support for the guidance above that ICBs can take cost into account in making decisions about how to offer to discharge their duties. A number of ICBs have policies which provide that a home-care package will be supported as long as the cost is not more than a defined percentage, usually 10%, greater than the cost of an equivalent care home placement. Although a legal challenge to this policy was threatened by the Equality and Human Rights Commission in about 2020 in the grounds that it was a breach of article 8 ECHR, that challenge never materialised and, as far as the authors are aware, this policy has been operated by a number of CCGs and now ICBs without challenge for at least a decade.

When and/or how can a patient or their family contribute towards the cost of a CHC package so as to maintain a patient in the location of their choice?

- 188. Once it is accepted that an ICB can limit the range of locations or services as part of a CHC package, questions may arise as to whether it is lawful for a patient or the patient's family to share the costs of an overall package, and thus bring the costs of a package in the patient's location of choice (typically their own home or in a more expensive care home) to a level that the ICB is prepared to pay. In this delicate area it can be significant to identify whether restrictions on allowing patients or their families to make financial contributions to the overall care package are (a) as a result of legal constraints or (b) are the result of policy recommendations which lean against mixing privately funded and NHS funded care services. The distinction is important because an ICB has an absolute duty to abide by legal restrictions but only has a duty to "have regard" to policy recommendations made by the DHSC and NHS England.
- 189. There is a key difference between NHS and social services care in 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 ICB is prepared to fund. Direct cost sharing is prohibited by s1 of the NHSA 2006 which provides:

"The services provided as part of the health service in England must be free of charge except in so far as the making and recovery of charges is expressly provided for by or under any enactment, whenever passed"

- 190. Regulations have not been made allowing an ICB to impose charges for the provision of services that make up a CHC package, and accordingly any services that the ICB provides must be provided free of charge. It follows that any arrangement under which a patient or relatives make a financial contribution towards the delivery of NHS services is unlawful. However, a large number of home care CHC packages in are not delivered by NHS staff but by carers employed or engaged by private domiciliary care agencies. The ICB will have put in a place a Standard NHS Contract with the agency for the delivery of a defined range of NHS services. Equally, the vast majority of care homes are not run by NHS Trusts but by private operators and the ICB will have a Standard NHS Contract in place with the care home to deliver care to a patient who is eligible for CHC.
- 191. The NHS website gives the following guidance in relation to top up payments:

"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"

- 192. The use of the words "should be provided by different staff" in the last sentence arguably goes beyond NHS policy in the National Framework and beyond the reasoning in the case of *R* (Southall) v Dudley PCT [2009] EWHC 1780 (Admin) which is considered below.
- 193. There are several ways in which patients are entitled to purchase additional services that sit along NHS services. First, and most straightforwardly, patients can top up the services that are commissioned by the ICB as part of a CHC package. Patients always have the right to purchase additional services to those that the ICB's assessment has identified as necessary to meet their needs. This is explained at paras 294 to 302. It states at 296:

"Where an individual advises that they wish to purchase additional private care or services, ICBs 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, ICBs should offer to review the care package in order to identify whether a different package would more appropriately meet the individual's assessed needs"

- 194. PG54 and PG55 of the National Framework give examples of patients purchasing additional services. 99 The National Framework also makes reference to a DHSC policy document "Guidance on NHS patients who wish to pay for additional private care" from 2009¹⁰⁰. This guidance emphasises that, as long as a separation can be maintained between the privately funded care and the NHS funded care, there is no reason why NHS patients should be prevented from being able to either supplement their NHS care with privately funded care or substitute privately funded care for elements of NHS funded care.
- 195. Secondly, it appears that patients are allowed a measure of freedom to enter into top up contracts with a care provider under which they substitute NHS funded services with a more extensive package of services from the provider. That is the ratio of the one High Court case which considered a "top up" arrangement, and indicates that ICBs have considerably more flexibility than the above Guidance suggests. In *R* (Southall) v Dudley PCT [2009] EWHC 1780 (Admin), Mitting J considered a claim where a patient was complaining that the PCT was not meeting the full costs of his chosen care home. Mr Southall was accommodated in the Coach House, which was an annex to a large care home, Prestwood House. The PCT was prepared to meet the cost of a room in the main house at £471 per week but was not prepared to meet the additional cost of a room in the more luxurious Coach House part at a higher rate. The Judge noted that the PCT evidence showed:

⁹⁹ One example is a patient where "The ICB review her care plan and consider that one physiotherapy session a week is sufficient to meet her needs. Eileen decides that she would nevertheless like to purchase an additional session. She makes arrangements with a private physiotherapist for this purpose".

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- ".. NHS continuing health care was required to be provided free of charge and that it was not the policy of the defendant or the practice of the wider NHS to agree to pay part of the cost of the continuing health care, leaving the balance to be paid privately by the patient or his family. However, it has always been the case within the National Health Service that those who wish to enjoy what are known in National Health Service jargon as "hotel-type services", may do so at their own cost. Thus, ever since the foundation of the National Health Service there have been available within National Health Service hospitals enhanced facilities, such as individual rooms, available to patient who are willing to pay for such facilities, but the principle has always been, and remains, subject to exceptions recently canvassed in relation to drugs administered to those with life-threatening illnesses, that health care services are provided free"
- 196. The Judge thus accepted that, by analogy with enhanced facilities in NHS hospitals, there was nothing wrong in Mr Southall electing to pay the difference to secure a better room. The Judge said:

"By reference to what is on any view a fairly fine line, the defendant is thus able to provide free continuing health care while at the same time accepting that additional contributions can be made for facilities that may meet non-health care needs"

- 197. This decision is thus some support for an element of cost sharing, provided the ICB would be able to provide services to meet the person's assessed needs in the location at which they are provided.
- 198. Thirdly, and potentially of more significance, an approach can be developed which derives from the fundamental principle of NHS care that the duty is on an NHS commissioning body to offer services to a patient but NHS services can only be provided if the patient agrees to accept the offered service. This principle is implicit but not is not made explicit in para 294 of the National Framework which provides:

"The NHS care package provided should meet the individual's assessed health and associated social care needs as identified in their care plan. 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 local authorities, but the NHS element of the care should always be clearly identified"

199. This flexibility is confirmed at para 315 of the National Framework which states:

"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. ICBs should consider whether models such as assistive technology could meet some of these needs. Where individuals are assessed as requiring nursing care, ICBs 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. ICBs should not make assumptions about any individual, group or community being available to care for family members"

200. It is implicit in this Guidance that a patient, together with their family, retains a measure of control over the patient's needs. Hence, by way of example, a person who lives in a house that they own or rent does not have a need for accommodation. Equally, a patient whose spouse or relatives are prepared to provide overnight care for a patient will not have a "need" for NHS funded overnight care. In principle, there does not appear to be any reason why a patient would not be entitled to put paid overnight care in place and thus obviate the need for the NHS to provide that element of care a part of any care plan. A patient or their family may wish to do this if the reduction in the cost of the CHC care plan as a result of the paid services means that a home-care package is sustainable whereas, if the NHS had to fund all the elements of the care, the only financially sustainable model would be for the ICB to commission a placement for a person in a care home.

- 201. The authors are aware that some ICBs have recognised that one way to approach the flexibility needed to deliver person centred planning is to focus on the nature of the "assessed needs" of a person, allowing patients to take "needs" out of the assessment process where the patient or their family (or a Deputy) and made alternative arrangements to meet that aspect of the patient's needs. This approach allows ICB commissions to create a financial package to meet all assessed needs which allows a CHC eligible person to remain in their own home because the cost of bespoke provision becomes justifiable. This type of arrangement has been used where the patient has a compensation package which is can used to part-fund care costs. Although there is an argument that this approach conflicts with the policy recommendations set out in DHSC policy statements and the National Framework, the authors consider that this approach is lawful, meets the aims of being patient centred and is consistent with the National Framework¹⁰¹ as long as the ICB has had proper regard to the relevant parts of the National Framework before concluding such an arrangement.
- 202. Arrangements of this type are potentially more complicated where a person is eligible for CHC and wishes to live in a care home which has fees which are higher than an ICB is prepared to pay. The National Framework provides the following advice at para 309:

"Where an individual in an existing out of area placement becomes eligible for NHS Continuing Healthcare the care package may be of a higher cost than the responsible ICB would usually fund for the person's needs. The ICB should consider whether the cost is reasonable, taking into account the market rates in the locality of the placement. They should also consider whether there are other circumstances that make it reasonable to fund the higher rate. Examples might include: where the location of the placement is close to family members who play an active role in the life of the individual, or where the individual has lived there for many years and it would be significantly detrimental to the individual to move them"

203. That guidance makes it clear that the ICB has a discretion to exercise to decide whether to fund the higher costs or not, but is not obliged to do so. The authors

¹⁰¹ In part because the National Framework is classified as "guidance" and thus an ICB is entitled to depart from the National Framework if it has good reasons to do so.

are aware that one way in which this problem has been creatively solved is for the care home to enter into separate contracts with the patient and the ICB, the first covering the basic accommodation cost of a room and the second covering care and other hotel costs. If the patient, or the patient's family (or finance deputy) agrees to take over the basic accommodation costs, then the provision of accommodation ceases to be a need for the patient just as if the patient was living in their own home.

CHC patients who are admitted to hospitals as in-patients.

- 204. If a person is eligible for CHC and then is admitted to hospital, the community based package will not be needed for as long as the patient remains in hospital as an in-patient.
- 205. The question as to whether an ICB was under an obligation to ensure that the full CHC package of support is available to the person whilst in hospital was examined in R (JF) v NHS Sheffield Clinical Commissioning Group [2014] EWHC 1345 (Admin). Stuart-Smith J (as he then was) said:

"If, as is the case here, the CCG has commissioned the provision of all hospital services as are necessary to meet the reasonable requirements of its patients, it will have discharged its s. 3 duty. It does not have to go further and direct the provider of the hospital services how it should treat individual patients"

206. However, unless the ICB conducts a review, the duty to provide the community based package will immediately resume once the patient is discharged from hospital.

Legal issues arising out of providing a care package in a patient's home.

207. If the patient is to be provided with a care package in his or her 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. ICBs are entitled to contract out such care packages to domiciliary care providers. If this happens, the ICB should ensure there is an NHS Standard

Contract (possibly in the shorter form) between the domiciliary care provider and the ICB which covers the same areas as a contract with a care home (see above).

- 208. Guidance on managing domiciliary care is provided at paras 315 to 319 of the National Framework. The ICB needs to be mindful that, any domiciliary care provider that is using staff to deliver services in the patient's own home will result in the patient's home being the employee's place of work. A provider 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.
- 209. Problems can arise because the domiciliary care provider 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 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 his or her 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 ICB 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 ICB must consider whether the patient's home is a reasonably safe environment for staff to work in. While 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 domiciliary care provider in breach of its duty to its own staff. While 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. 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 ICB staff are aware of these types of problems, they should report them and seek advice and support without delay.

Part I: Support for patients who do not qualify for NHS CHC or NHS-funded nursing care.

- 210. If a patient does not qualify for CHC, the NHS is under no legal obligation to meet all or any part of the accommodation or social care costs of a patient who is not in hospital. However, the ICB may still be responsible for providing a broad range of healthcare services to the patient, including offering to provide primary care services from a general practitioner (GP) practice. Thus, the ICB 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.
- 211. The National Framework explains at para 289 that patients who do not qualify for CHC are still entitled to be considered for a range of NHS services (depending on the needs of the individual) including:
 - Primary healthcare
 - 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 healthcare
 - Community health services
 - Specialist health care support
 - Palliative care.

- 212. 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)¹⁰². However, if the ICB has properly followed the responsibilities directions, 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 ICB has got to the point of deciding that a patient is not eligible 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 ICB to plug the gaps.
- 213. 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 ICB does not of course need to meet every healthcare need), will have to be provided by NHS provided contractors. The core accommodation and social care costs, however, should not be met by the ICB.

Cost-sharing arrangements with local authorities outside CHC.

- 214. There is a widespread practice of 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 commissioning body and local authorities, often on a 50:50 basis. These arrangements result in NHS funds being used to meet part of the costs of accommodation and social care services for non-CHC patients. There is no legal basis for making such payments.
- 215. The *National Framework* guidance states: 103

¹⁰² See the discussion above concerning Reg 22(7) of the RSR Regs. ¹⁰³ At para 34.6.

"The ICB 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 any joint care package"

- 216. Thus, where a patient is not eligible for CHC, the responsibility on the ICB is only entitled 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, ICBs 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 is further explained at PG51 in the National Framework.
- 217. The scope and limits on the duties of the NHS to provide accommodation was set out by HHJ Hickinbottom (later Hickinbottom LJ) in *Secretary of State for Work and Pensions v Vale and others*¹⁰⁴ 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.

¹⁰⁴ CDLA/3161/2003 dated 27 July 2005.

However, that must be a matter of choice, exercised by someone competent to make the relevant decision.

218. This is probably still good law despite the Court of Appeal's decision in *Whapples* but legal advice should be sought if needed. Thus if the ICB enters into a 50:50 cost sharing arrangement for a patient who does not qualify for CHC, the ICB may well be contributing to the cost of the patient's accommodation in circumstances where the ICB has not power to meet any part of the patient's accommodation costs. The better approach is for the ICB to work out the (approximate) cost of the healthcare inputs into the package which the ICB 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 ICB this can be resolved using the dispute resolution process set out above.

Part J: Subsequent review of CHC decisions for eligible patients

219. 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 three 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.

Part K: Special categories of patients

- 220. 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) Care for patients who are in a terminal phase of life;
 - c) Adults with learning difficulties;
 - d) Former long-stay patients;
 - e) Patients where there are specific funding care agreements; and
 - f) Patients leaving in-patient mental health care under section 117 of the Mental Health Act (MHA) 1983.

Children.

221. CHC is a framework that only applies to adults. The position is relation to children is subject to separate guidance and is considered in a separate guide.

Care for patients who are in a terminal phase of life

222. Patients who have a rapidly deteriorating condition and may be entering a terminal phase are assessed for CHC entitlement under a separate fast track decision-making process¹⁰⁵. The National Framework explains at para 240:

"The Government's End of Life Care Choice Commitment sets out what everyone should expect from their care at the end of life, and the action being taken to make high quality and personalisation a reality for all"

223. That passage cross references to a separate DHSC document from 2016 namely "Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care¹⁰⁶". The commitments made in that document are as follows:

"Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:

- have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die;
- make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families;
- develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness;

¹⁰⁵ See para XX above.

¹⁰⁶ See

- share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care;
- involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care;
- know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way"
- 224. The balance of the document refers to the plans that DHSC sought to put in place to ensure that the NHS can deliver on the commitments made to manage the period up to death in a way that best reflected the person's wishes.

Adults with learning disabilities.

- 225. 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.
- 226. 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 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 RSR Regs 2012 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.
- 227. The issues are accurately summarised at PG35¹⁰⁷ which provides:

¹⁰⁷ See National Framework p80.

"PG35: 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.

35.4 The reasons given for a decision on eligibility should not be based on the:

- (a) individual's diagnosis;
- (b) setting of care;
- (c) ability of the care provider to manage care;
- (d) use (or not) of NHS-employed staff to provide care;
- (e) need for/presence of 'specialist staff' in care delivery;
- (f) the fact that a need is well-managed;
- (g) the existence of other NHS-funded care; or
- (h) 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 healthcare. 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, ICBs have considerable existing legal powers to maximise choice and control, including the provision of 'personal health budgets'. Anyone in receipt of NHS Continuing Healthcare has the right to have a personal health budget which could potentially include a 'direct payment for healthcare'. These arrangements include individuals with a learning disability and ICBs should ensure that they are aware of current legislation and guidance on this matter

- 38.11 Whatever the outcome of the eligibility decision regarding NHS Continuing Healthcare, commissioning should be person-centred and needs-led. Where an individual is eligible for NHS Continuing Healthcare, ICBs 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 ICB.
- 228. While cases are, of course, fact-specific, a number of ICBs 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 or, having regard to the above guidance, a primary need for social care support.

Former long-stay patients.

- 229. 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 NHS Act 2006. However, these are payments by ICBs 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 ICB has statutory responsibility.
- 230. 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 Guide.

Patients where there are specific funding care agreements.

- 231. There are some patients or groups of patients where the NHS has entered into long-term agreements with local authorities for support the social care costs for those patients. These agreements can take one of two forms, namely:
 - a) Section 75 agreements in which local authorities agreed to provide specified health care services on behalf the ICB; or
 - b) Section 256 agreements under which the ICB 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.
- 232. 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.

Patients leaving mental health detention: section 117 of the Mental Health Act 1983.

- 233. Patients who are leaving detention under section 3 of the Mental Health Act 1983 ("MHA 1983") have a legal right under section 117 MHA 1983 to a package of after care services. The obligation to provide (and hence fund) aftercare services is jointly owed by an ICB and the relevant local authority. It is an entirely separate legal duty from CHC funding. In general, s117 patients are entitled to a package of support arising from their mental health needs without the need to be assessed under the CHC regime.
- 234. The primacy of the s117 duty over the CHC regime is explained at paras 333 to 343 of the National Framework. 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. Para 338 of the National Framework explains:

"It is not, therefore, necessary to assess eligibility for NHS Continuing Healthcare if all the services in question are in fact to be provided as aftercare services under section 117"

235. However, CHC may be relevant for a patient in receipt of s117 support where that person has some needs that are related to their mental health condition and others that arise independently. Para 339 of the National Framework explains:

"However, a person in receipt of after-care services under section 117 may for example have ongoing needs that do not arise from, or are not related to, their mental disorder and that may, therefore, not fall within the scope of section 117. Also a person may be receiving services under section 117 and then develop separate physical health needs (e.g. through a stroke) which may then trigger the need to consider NHS Continuing Healthcare, but only in relation to these separate needs, bearing in mind that NHS Continuing Healthcare must not be used to meet section 117 needs. Where an individual in receipt of section 117 services develops physical care needs resulting in a rapidly deteriorating condition which may be entering a terminal phase, consideration should be given to the use of the Fast Track Pathway Tool"

236. Hence, in the unusual case of a patient who has physical and mental health needs, the patient would fall to be assessed for their physical needs under the CHC system and would be entitled to support for their mental health needs 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 ICBs can agree to meet 50 per cent of the costs of a care package.

Part K: Direct payments for NHS CHC patients.

237. 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 known as a Personal Health Budgets ("PHB")¹⁰⁸. Para 321 of the National Framework makes it clear that CHC eligible patients have the same right to a PHB as other patients with long term disabilities. However, where a patient is in a care home and there is a single payment to the care home provider, there is little point in setting up a PHB arrangement and it is arguable whether the ICB is under any legal duty to do so.

¹⁰⁸ See chapter 14 for details of Personal Health budgets.