

Direct Payments and Personal Health Budgets

List of terms and abbreviations used in this chapter:

| | |
|----------------------|---|
| NHS Act | The National Health Service Act 2006 |
| DPA | The Data Protection Act 1998 |
| 2013 Regulations | The National Health Service (Direct Payments) Regulations 2013 |
| MCA | The Mental Capacity Act 2005 |
| The Guidance | The NHS England Guidance called “Guidance on Direct Payments for Healthcare: Understanding the Regulations” |
| Health Body | A CCG, NHS England, the Secretary of State or a local authority having social services functions. |
| The 2012 Regulations | The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012. |

1. Introduction

- 1.1 The introduction of direct payments, often referred to as Personal Health Budgets (“PHBs”) could be seen as a quiet revolution in the way that the NHS delivers on its statutory duties to fund NHS services to patients.
- 1.2 The traditional model is for the patient to be provided with services commissioned by an NHS commissioner and provided by an NHS provider which is under contract to the commissioner. There is no contractual or financial relationship between the patient and the NHS provider and the services that the patient has access to are those set out in the commissioning contract. Direct payments could not be more different. The whole purpose of a direct payment is to make the patient the commissioner for their own care. Hence health (and potentially social care) care is delivered to the patient pursuant to a direct payment arrangement under contracts between the patient and the care provider, not set up by an NHS commissioner. Operating a direct payment thus involves a substantial transfer of control, risk and responsibility from the NHS commissioner to the patient.

1.3 Direct payments raise a series of potentially difficult legal issues, including establishing systems to ensure there is proper financial and clinical governance in the operation of the packages. Direct payments were trialled by the NHS and a 215 page report was published concerning the outcome of a research project¹. The main findings were:

“The main benefit-related implications of personal health budgets were as follows (unless otherwise noted, significance is assessed at the 95% confidence level):

- The use of personal health budgets was associated with a significant improvement in the care-related quality of life (ASCOT) and psychological well-being (GHQ-12) of patients (at 90% confidence).
- Personal health budgets did not appear to have an impact on health status per se over the 12 month follow-up period. No significant effects were found with regard to two clinical measures (HbA1C and lung-function tests, used where relevant) and there was no significant difference in mortality rates between the groups. Consistent with these results, the study did not find that personal health budgets had a significant effect on EQ-5D compared to the control group”

1.4 Hence, patients felt significantly better if they had a measure of control over their own healthcare services but it did not necessarily improve objective health outcomes. The research findings about cost were as follows:

“The main findings of the cost analysis were:

- The cost of inpatient care (an ‘indirect’ cost) was significantly lower for the personal health budget group compared to the control group after accounting for baseline differences.
- The (‘direct’) costs of well-being and other health services were both significantly higher for the personal health budget group compared to controls.
- Other categories of direct and indirect cost showed no difference between the groups.
- The difference in direct and indirect total costs between personal health budget and control groups after accounting for baseline differences were not statistically significant”

1.5 Perhaps the message from this finding was that it cost more NHS money directly to provide care to someone under a direct payment but the patient ended up in hospital for in-patient treatment less and so overall they represented value for money.

¹ See

http://www.personalhealthbudgets.dh.gov.uk/library/Resources/Personalhealthbudgets/2012/PHBE_personal_health_budgets_final_report_Nov_2012.pdf

- 1.6 Direct payments are now governed by the National Health Service (Direct Payments) Regulations 2013 (“the 2013 Regulations”) and, for patients in receipt of NHS Continuing Healthcare or Continuing Care for Children, by Part 6A of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 (as amended by the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013). The 2013 Regulations have been amended since they were first made. The version referred to here is the version in effect on 1 December 2016. The 2013 Regulations are supplemented by statutory guidance published by NHS England “Guidance on Direct Payments for Healthcare: Understanding the Regulations²”. There is separate Guidance on the “right to have” a direct payments for patients who are eligible for NHS Continuing Healthcare³ as a result of changes to the legal regime around direct payments arising from the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) (No3) Regulations 2014.
- 1.7 This chapter will look at the rules on direct payments that apply to all cases. The special rules concerning patients in receipt of NHS Continuing Healthcare or Continuing Care for Children will be considered at part 14 below.
- 1.8 The first attempt to persuade an NHS body to use direct payments occurred in *R (Harrison) v Secretary of State for Health & Ors* [2009] EWHC 574 (Admin). Mr Harrison⁴ had a social care direct payment but he was then assessed to be eligible for NHS continuing healthcare. As a result, responsibility for funding services for him switched from the local authority to the NHS. He had had the benefit of social care direct payments which he and asked for the arrangements to be continued once his care. However, the NHS said that it had no power to provide direct payments and could only fund services provided to Mr Harrison. The Judge noted that the Department of Health noted the benefits of direct payments. He said at §21:

² See http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/2014/Guidance_on_Direct_Payments_for_Healthcare_Understanding_the_Regulations_March_2014.pdf

³ See http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/2014/Personal_health_budgets_right_to_have_guidance.pdf

⁴ There was a second claimant who was in a similar position.

“There is clear evidence that direct payments for medical care increase both the claimants' degree of choice and flexibility in relation to medical care as well as enhancing their autonomy so that a greater degree of independent living can be enjoyed by each of them. Indeed this is not in dispute as in the witness statement adduced by the defendant from Mr Andrew Sanderson a civil servant in the Department of Health, he accepted that:-

"research suggests that direct payments have substantially increased the satisfaction of the recipient as well as delivering better outcomes and greater independence than traditional social care models".

1.9 However the Judge accepted the Secretary of State's submissions that the duty to provide “services” under section 3(1) of the National Health Service act 2006 (“the NHS Act”) could not be discharged by the provision of money to a patient, even if that money was provided with the intention of allowing the patient to purchase his own services.

1.10 This legislative lacuna was corrected by section 11 of the Health Act 2009 which introduced a new section 12A into the NHS Act. The present version of section 12A is as follows:

“(1) The Secretary of State, the Board, a clinical commissioning group or a local authority may, for the purpose of securing the provision to a patient of anything to which this subsection applies, make payments, with the patient's consent, to the patient or to a person nominated by the patient.

(2) Subsection (1) applies to—

(a) anything that the Secretary of State or a local authority has a duty or power to provide or arrange under section 2A or 2B or Schedule 1;

(aa) anything that the Board or a clinical commissioning group may or must arrange for the provision of under this Act or any other enactment.

(b) ...

(c) ...

(3) Subsection (1) is subject to any provision made by regulations under section 12B.

(4) If regulations so provide, a clinical commissioning group may, for the purpose of securing the provision for a patient of services that the group must provide under section 117 of the Mental Health Act 1983 (after-care), make payments, with the patient's consent, to the patient or to a person nominated by the patient; and the references in this subsection to a clinical commissioning group are, so far as necessary for the purposes of regulations under subsection (2E) of that section, to be read as references to the Board.

(5) A payment under subsection (1) . . . is referred to in this Part as a “direct payment”.

(6) . . .

(7) In this section and sections 12B to 12D, “local authority” has the same meaning as in section 2B”

1.11 Section 12B provided Regulation making powers which were used to make the 2013 Regulations. Section 12C provided for direct payments to be subject to pilot arrangements. Those pilot arrangements have now come to an end and direct payments are generally available to NHS patients in appropriate circumstances.

1.12 The next significant change arose in October 2014 when changes were made to the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 to give patients who were eligible for NHS continuing Healthcare and Children and Young Person’s continuing care a qualified “right” to insist that they have direct payments. The nature of this right and the qualifications are examined below.

1.13 Today direct payments are an established method of funding community health services for large numbers of patients. They are widely used but, as far as I know, there are no published statistics about how many direct payment arrangements are operating in the English NHS. It is possible for patients to have both profound physical and mental health needs. In that case, a patient would fall to be assessed for their physical needs under the CHC system and would be entitled to support under section 117. Aside from such unusual circumstances, patients being discharged from compulsory in-patient mental health should not be assessed for CHC.

2 Who is ineligible to apply for a PHB?

2.1 Most NHS patients have the right to apply for a direct payment (although no patient can be forced to have one). However, there is a list of patients who are excluded from the right in the Schedule to the 2013 Regulations. None of the following persons have a right to seek to have a direct payment:

(a) Anyone subject to a **drug rehabilitation requirement**, as defined by section 209 of the Criminal Justice Act 2003 (drug rehabilitation requirement), imposed by a

community order within the meaning of section 177 of that Act (community orders), or by a suspended sentence of imprisonment within the meaning of section 189 of that Act (suspended sentences of imprisonment);

(b) Anyone subject to an **alcohol treatment requirement** as defined by section 212 of the Criminal Justice Act 2003 (alcohol treatment requirement), imposed by a community order, within the meaning of section 177 of that Act, or by a suspended sentence of imprisonment, within the meaning of section 189 of that Act;

(c) Anyone **released on licence** under Part 2 of the Criminal Justice Act 1991 (early release of prisoners), Chapter 6 of Part 12 of the Criminal Justice Act 2003 (release, licences and recall) or Chapter 2 of Part 2 of the Crime (Sentences) Act 1997 (life sentences) subject to a non-standard licence condition requiring the offender to undertake offending behaviour work to address drug or alcohol related behaviour;

(d) Anyone **required to submit to treatment for their drug or alcohol dependency by virtue of a community rehabilitation order** within the meaning of section 41 of the Powers of Criminal Courts (Sentencing) Act 2000 (community rehabilitation orders) or a community punishment and rehabilitation order within the meaning of section 51 of that Act (community punishment and rehabilitation orders);

(e) Anyone subject to a **drug treatment and testing order** imposed under section 52 of the Powers of Criminal Courts (Sentencing) Act 2000 (drug treatment and testing orders);

(f) Anyone subject to a **youth rehabilitation order** imposed in accordance with paragraph 22 (drug treatment requirement) of Schedule 1 to the Criminal Justice and Immigration Act 2008 (“the Criminal Justice Act 2008”) which requires the person to submit to treatment pursuant to a drug treatment requirement;

(g) Anyone subject to a **youth rehabilitation order** imposed in accordance with paragraph 23 of Schedule 1 to the Criminal Justice Act 2008 (drug testing requirement) which includes a drug testing requirement;

(h) Anyone subject to a **youth rehabilitation order** imposed in accordance with paragraph 24 of Schedule 1 to the Criminal Justice Act 2008 (intoxicating substance treatment requirement) which requires the person to submit to treatment pursuant to an intoxicating substance treatment requirement;

(i) Anyone who is either—

(i) subject to a **drug treatment and testing order** within the meaning of section 234B of the Criminal Procedure (Scotland) Act 1995 (drug treatment and testing order), or

(ii) subject to a **community payback order** under section 227A of that Act imposing requirements relating to drug or alcohol treatment; or

(j) **released on licence** under section 22 (release on licence of persons serving determinate sentences) or section 26 of the Prisons (Scotland) Act 1989 (release on licence of persons sentenced to imprisonment for life, etc) or under section 1 (release of short-term, long term and life prisoners) or section 1AA of the Prisoners and Criminal Proceedings (Scotland) Act 1993 (release of certain sexual offenders) and subject to a condition that they submit to treatment for their drug or alcohol dependency.

2.2 These are fairly narrow categories and mostly involve persons who are within the criminal justice system. Any other patient has the right to seek direct payments.

2.3 Where a patient sets up a direct payment arrangement and subsequently comes within one of the above categories, the health body is obliged to bring the direct payment to an end and resume commissioning services for the patient because the health body has no vires to continue with a direct payment for anyone in the categories set out in the Schedule to the 2013 Regulations.

3 **What services cannot be funded by direct payments?**

3.1 The 2013 Regulations does not define a list of NHS services that can be funded by direct payments. Instead, it defines a list of services that are outside the scope of direct payments.

Regulation 8(5) provides that a direct payment arrangement cannot be entered into to fund the provision of any of the following services to a patient:

- (a) Primary care services, namely those arranged or provided under sections 83 (primary medical services), 84 (general medical services contracts) or 92 (arrangements by the Board for the provision of primary medical services) of the 2006 Act;
- (b) Any services where a charge is made to the patient for the service (by virtue of sections 172 (charges for drugs, medicines or appliances, or pharmaceutical services), 176 (dental charging) or 179 (charges for optical appliances) of the 2006 Act);
- (c) Planned surgical procedures;
- (d) Providing vaccination, immunisation or screening, including population-wide immunisation programmes;
- (e) Services provided under the National Child Measurement Programme;
- (f) Services provided as part of an NHS Health Check;
- (g) Services which consist of the supply or procurement of alcohol or tobacco;
- (h) Services which consist of the provision of gambling services or facilities; or
- (i) Services to repay a debt otherwise than in respect of a service specified in the care plan.

3.2 In addition the Guidance provides at paragraph 24:

“A direct payment cannot be used for urgent or emergency treatment services, such as unplanned in-patient admissions to hospital or accident and emergency. This is because by their very nature they are unplanned and so will not have been included in a care plan. Whilst CCGs should not include services which require unplanned emergency access they may want to develop advance directives or crisis planning to ensure that people’s wishes are taken into account when a crisis happens or that they have increased support or services to prevent the need for emergency care or hospital admission”

3.3 The Guidance also notes in a cautionary way at paragraph 27:

“In addition they cannot be used to purchase anything illegal or unlawful”

So, at least for the time being, medicinal cannabis probably cannot be funded out of a direct payment.

3.4 It follows that a direct payment arrangement can be set up to fund any other health, social care or other service that a patient needs on a regular basis other than those described above and which is a service of a nature that the health body would commission for the patient. This is confirmed in the Guidance which says as follows at paragraph 28:

“In principle, other than the services listed in paragraphs 22 to 27, a direct payment can be spent on a broad range of things that will enable the person to meet their health and wellbeing needs”

4 Which Health Bodies can set up a direct payment arrangement?

4.1 Direct payments can be set up by⁵:

- a) A clinical commissioning group;
- b) NHS England;
- c) Some local authorities; and
- d) The Secretary of State.

4.2 The only local authorities that can set up NHS direct payments are:

- a) a county council in England;
- b) a district council in England, other than a council for a district in a county for which there is a county council;
- c) a London borough council;

⁵ See the definition of “health body” in Regulation 2 of the 2013 Regulations.

d) the Council of the Isles of Scilly; and

e) the Common Council of the City of London.

4.3 Clinical commissioning groups and NHS England can set up a direct payment arrangement under the 2013 Regulations in order to provide services that they are authorised to provide under any Act of Parliament. In contrast, local authorities can only set up a direct payment arrangement under the 2013 Regulations where they have duties to a patient under the NHS Act. Local authorities have powers to set up direct payments in discharge of their community care duties under the Care Act 2014 under the Care and Support (Direct Payments) Regulations 2014. Community care direct payment arrangements under those Regulations have a number of features which are different to NHS direct payment arrangements⁶.

4.4 In practice, local authorities are most likely to become parties to NHS direct payment arrangements involving complex services to disabled children (as to which see below). It is hard to see how local authorities are likely to make use of direct payments to discharge their public health duties under the NHS Act.

5 The key players in any direct payment arrangement.

5.1 The 2013 Regulations define a series of roles that can or are required to be carried out in the setting up and operation of a direct payment arrangement. The primary roles are:

- a) The patient;
- b) The representative;
- c) The nominated person;
- d) The care co-ordinator; and
- e) Support Organisations.

5.2 **The Patient:** The patient is the person to whom the health body owes the primary legal duty to provide services and is the beneficiary of the direct payment arrangement. The health body owes public law duties to provide health and/or social care services to the patient and seeks to discharge that duty by making payments under a direct payment arrangement

⁶ The operation of community care direct payment arrangements is beyond the scope of this chapter.

instead of commissioning services from one or more providers to provide services to the patient. The patient can be a child or an adult and may or may not have capacity to make their own medical treatment decisions or have capacity to manage the direct payment (in which case it must be managed via a representative).

5.3 The Representative: The representative is the person who takes legal responsibility for the direct payment arrangements when the patient is unable to do so because the patient is either a child or is an adult who lacks capacity. Regulation 2 defines the list of persons who can be appointed to be a representative as follows:

- a) any deputy who has been appointed by the Court of Protection under section 16(2)(b) of the Mental Capacity Act 2005 (“the MCA”) (powers to appoint deputies) to make decisions on that person's behalf in relation to matters in respect of which direct payments may be made;
- b) any donee of a lasting power of attorney within the meaning of section 9 MCA (lasting powers of attorney) to make decisions on that person's behalf in relation to matters in respect of which direct payments may be made;
- c) any attorney in whom the power is vested in the case of a person who has created an enduring power of attorney within the meaning of Schedule 4 MCA (provisions applying to existing enduring powers of attorney), which is registered in accordance with paragraphs 4 and 13 of that Schedule or in respect of which an application has been made for such registration;
- d) any person with parental responsibility for a child who is the beneficiary of a direct payment arrangement;
- e) any person with parental responsibility for a child who lacks capacity between the ages of 16 and 18; or
- f) any other person appointed by the health body to be a representative for a person who lacks capacity under regulation 5(4), which permits the appointment of someone to be

a representative for a patient who lacks capacity where no one is proposed on behalf of the patient.

- 5.4 The references to “capacity” in the above paragraphs are a reference to the capacity of the patient to consent to the making of a direct payment to them, applying the capacity tests under the Mental Capacity Act 2005: see Regulation 5(1). Capacity is, of course, a decision specific test and a patient with limited cognitive functions may have capacity to take some types of decision for himself or herself but not have capacity to take other decisions. Patients can also have fluctuating capacity. The legal structures arising in connection with direct payment arrangements for patients who lacks capacity are considered in more detail below.
- 5.5 The categories of persons who can be a representative are limited to those set out in paragraph 5.3 above. The 2013 Regulations do not permit a patient who has capacity to nominate someone to be their representative, even if this would assist the smooth operation of the direct payment arrangements. Hence, a patient with capacity who wants the benefit of a direct payment arrangement must be prepared to become a party to the direct payment arrangement and take on the legal responsibilities associated with the direct payment arrangement. The capacitous patient can be assisted by a “nominated person” (as explained below) but must take on the legal burden of being a party to the direct payment arrangement. Paragraph 83 of the Guidance explains the role of the representative as follows:

“83) A representative is responsible for managing direct payments on behalf of the person receiving care. They, or their nominee, must:

- act on behalf of the person, e.g. to help develop care plans and to hold the direct payment;
- act in the best interests of the person when securing the provision of services;
- be the principal person for all contracts and agreements, e.g. as an employer;
- use the direct payment in line with the agreed care plan;
- comply with any other requirement that would normally be undertaken by the person as set out in this guidance (e.g. review, providing information).

84) If a representative believes that the person for whom they are acting has regained capacity they should notify the CCG as soon as possible (see paras 47-49 on fluctuating capacity)”

5.6 **The nominated person:** Regulation 6 of the 2013 Regulations refers to the role of the “nominated person”. This is a person who is nominated by the patient or the patient’s representative to “receive a direct payment”: see Regulation 6(1). The Guidance explains the difference between nominees for NHS direct payments and nominees for social care direct payments at paragraph 66 as follows:

“It is important that CCGs and their commissioning and provider partners understand that the role of nominee for direct payments for healthcare is different from the role of nominee for direct payments for social care. For social care direct payments, a nominee does not have to take on all the responsibilities of someone receiving direct payments, but can simply carry out certain functions such as receiving or managing direct payments on behalf of the person receiving them. In direct payments for healthcare, however, the nominee is responsible for fulfilling all the responsibilities of someone receiving direct payments, as described below in Box 2. People aged 16 or over with capacity and representatives receiving direct payments for healthcare, and those who act as their nominees need to be made fully aware of this particularly if they have previous experience of appointing or acting as a nominee under the social care arrangements”

5.7 The wording in “Box 2” explaining the legal duties of the nominee is as follows:

“What is a nominee?

A nominee is responsible for managing the direct payment on behalf of the person receiving care. They are responsible for fulfilling all the responsibilities of someone receiving direct payments. These include:

- a. acting as the principal person for all contracts and agreements with care providers, employees, etc;
- b. using the direct payment in line with the agreed care plan; and
- c. complying with any other requirement that would normally be undertaken by the person receiving care as set out in this guidance (e.g. review, providing financial information)”

5.8 Regulation 6(3) sets out the legal duties of the nominee as follows:

“A nominee to whom a direct payment is made in respect of a patient must—

- (a) be responsible as a principal for all contractual arrangements entered into for the benefit of the patient and secured by means of the direct payment;
- (b) use the direct payment in accordance with the care plan; and
- (c) comply with the relevant provisions of these Regulations”

5.9 In practice, this means that a nominee takes on considerable legal obligations. The nominee must be a joint employer with the patient or representative under any contract of employment with a care worker. The nominee must also become a contracting party with an agency which is providing care workers for the patient. Thus, if the care worker is dismissed, both the nominee and the patient would be Respondents to an application to an employment tribunal. The nominee has a legal duty to ensure that the NHS money provided under the direct payment is used for the purposes set out in the care plan and for no other purposes. The nominee also has a duty to ensure that there is compliance with all of the duties under the Regulations.

5.10 No one can be forced to act as a nominee. The nominee must give their consent to take on this role and can resign his or her responsibilities at any time. A nominee can be a company as well as an individual. There is nothing expressly set out in the 2013 Regulations or the Guidance which refers to the question as to whether a nominee can be paid for undertaking these duties. However, in practice nominees are regularly paid by CCGs for supporting direct payment arrangements. Paragraph 72 of the Guidance recognises that organisations can be established to act as nominees to support direct payment arrangements. These organisations perform a valuable role in assisting the patient or their representative to employ care staff, manage timesheets, wages, rotas and pension arrangements. Such organisations could only operate if they were paid for undertaking this role and the costs of the nominee must therefore be built into the costs of the care plan.

5.11 Paragraph 70 of the Guidance explains the need for the nominee (or individuals representing a corporate nominee) to provide Criminal Record Bureau clearance as follows:

“If the proposed nominee is not a close family member of the person living in the same household as the person, or a friend involved in the person’s care, then the CCG must require the nominee to apply for an enhanced Disclosure and Barring Service (DBS) certificate (formerly a CRB check) with a check of the adults’ barred list and consider the information before giving their consent. If a proposed nominee in respect of a patient aged 18 or over is barred the CCG must not give their consent. This is because the

Safeguarding Vulnerable Groups Act 2006 prohibits a barred person from engaging in the activities of managing the person's cash or paying the person's bills"

5.12 **The Care Co-ordinator:** Regulation 8(3) of the 2013 Regulations provides that the health body must appoint a specific individual to be the care co-ordinator in relation to every direct payment. The Regulation provides that the duties of the care co-ordinator are as follows:

"A health body must nominate a care co-ordinator who is to be responsible for the following functions in respect of the patient—

- (a) managing the assessment of the health needs of the patient for the care plan;
- (b) ensuring that the patient or their representative has agreed to the matters listed in paragraph (7);
- (c) monitoring or arranging for the monitoring of—
 - (i) the making of direct payments, and
 - (ii) the health conditions of the patient in respect of which the direct payments are made;
- (d) arranging for review of the direct payments; and
- (e) liaising between the patient or the representative or nominee and the health body in relation to the direct payments.

5.13 The reference to a "the matters in paragraph (7)" in Regulation 8(3) above is a reference to Regulation 8(7) which provides that, before a direct payment is set up, the patient or their representative must agree:

- (a) that the patient's specified health needs can be met by the services specified in the care plan;
- (b) that the amount of the direct payments is sufficient to provide for the full cost of each of the services specified in the care plan; and
- (c) that the patient's requirements may be reviewed in accordance with regulation 14(2) which provides for monitoring and review of direct payments.

- 5.14 The care co-ordinator is not required to have any specific qualifications but is typically a nurse or other healthcare professional employed by a CCG. The role of the care co-ordinator is explained at paragraphs 115 and 116 of the Guidance as follows:

“115) The care coordinator should normally be someone who has regular contact with both the individual receiving care, and their representative or nominee if they have one. They do not need to have ‘care coordinator’ in their job title - the important thing is that they fulfil the responsibilities above and that the direct payment recipient is aware of who they are and their role. While they are able to arrange with others to undertake actions, such as monitoring or review, the care coordinator should be the primary point of contact between the individual and the CCG. This is a similar role to the care coordinator in many mental health services and community matrons in NHS Continuing Healthcare.

116) It is the responsibility of CCGs to decide who is best placed in their organisations to take up the role of care coordinator. Different services such as mental health services already have best practice guidance around the role of the care coordinator. CCGs may also find it helpful to build on the experience of local authorities”

- 5.15 **Support Organisations:** There is no reference in the 2013 Regulations to “Support Organisations”. However Support Organisations are involved in many direct payment arrangements. The roles undertaken by such organisations is noted at paragraph 75 of the Guidance as follows:

“The status of support organisations with regard to the role of nominee

An organisation which does not have the status of a nominee but provides financial management and support services to the person who receives and manages direct payments for an individual, their representative or nominee, is not considered to be acting as a nominee as defined by the regulations. In this situation the individual, their representative or nominee remain fully responsible for the direct payment, including acting as the employers of any personal assistant/s and the making of decisions about their direct payment. The organisation may offer advice and support around a number of elements including being an employer, in addition to coordinating the financial element of the direct payment but they do not take on full responsibility for the person’s care and budget”

- 5.16 This Guidance suggests that a care plan can build in the costs of an organisation whose role is to support the patient or representative in managing the arrangements. A Support Organisation differs from a nominee because it is not a party to a direct payment agreement, does not receive the direct payment money and does not become the employer of any staff engaged to support the patient or contractually responsible under, for example, a domiciliary care contract. However, even though it is not formally a nominee under the Regulations, a

support organisation could provide the same type of practical support as a nominee, namely assisting in employing staff, managing rotas, making payments and handling the paperwork. The key difference is that a nominee has a direct relationship with the commissioning health body whereas a support organisation provides these services under contract to the patient or representative.

6 The decision-making process leading to offer of a direct payment arrangement.

6.1 The scheme of the Regulations envisages the following stages to the setting up of a direct payment arrangement with a patient or their representative:

- a) The patient or their representative approaches the health body to request a direct payment;
- b) The health body makes a “capability” decision;
- c) The health body nominates a care co-ordinator and then prepares the care plan;
- d) The cost of delivering the care plan is calculated and a budget is proposed,
- e) The care plan and the amount of the direct payment are agreed with the patient or their representative; and
- f) Once the care plan and the budget are agreed, the health body and the patient (or their representative) makes a final decision whether to proceed with the direct payment arrangement and, at that point, the health body stops commissioning relevant services for the patient and services are commissioned under the direct payment arrangement.

6.2 Although the Regulations separate out the capability decision from decisions about the care plan and financial decisions, in practice none of these stages are wholly independent since they all depend on each other. However, as the Regulations identify different decisions at different stages, it is necessary to consider the stages separately in order to describe the legal structures around direct payment decision-making.

7 The Capability Decisions under Regulation 7 of the 2103 Regulations.

7.1 Regulation 7 of the 2013 Regulations contains a detailed, mandatory decision-making process that the health body is required to follow when making an “in principle” decision whether to set up a direct payment arrangement. It provides:

“(1) A health body must make any decision to make a direct payment to, or in respect of, a patient in accordance with this regulation.

(2) Before deciding whether to make a direct payment to a patient, a health body—

(a) may consult the following persons—

(i) anyone identified by the patient as a person to be consulted for the purpose,

(ii) if the patient is a person aged 16 or over but under the age of 18, a person with parental responsibility for the patient,

(iii) the person primarily involved in the care of a patient,

(iv) any other person who provides care for the patient,

(v) any independent mental capacity advocate or independent mental health advocate appointed for the patient,

(vi) any health care professional or other professional person who provides health services to the patient,

(vii) any local authority social care team that is responsible for ensuring that the patient's social care needs are met, or

(viii) any other person who appears to a health body to be able to provide information of relevance;

(b) may require the patient to provide information relating to—

(i) the patient's state of health,

(ii) any health condition of the patient in respect of which a direct payment is contemplated, and

(iii) any bank, building society, post office or other account into which a direct payment may be made; and

(c) must be satisfied that the patient is capable of managing a direct payment by themselves or with the assistance that may be available to them.

(3) Before deciding whether to make a direct payment in respect of a patient to the representative of the patient, a health body may consult—

(a) the patient;

(b) any deputy appointed in respect of the patient by the Court of Protection under section 16(2)(b) of the 2005 Act (powers to appoint deputies) who lacks authority to make decisions on behalf of the patient in relation to matters in respect of which direct payments may be made;

- (c) any donee of a lasting power of attorney within the meaning of section 9 of the 2005 Act (lasting powers of attorney) in respect of the patient but who lacks authority to make decisions on behalf of the patient in relation to matters in respect of which direct payments may be made;
 - (d) the persons mentioned in paragraph (2)(a)(iii) to (viii); and
 - (e) anyone named by the patient, when the patient had capacity, as a person to be consulted for this purpose.
- (4) Before deciding whether to make a direct payment in respect of a patient to the representative of the patient, a health body—
- (a) may require the representative to provide information relating to any bank, building society, post office or other account into which the direct payment may be made; and
 - (b) must be satisfied that the representative is capable of managing a direct payment by themselves or with the assistance that may be available to them.
- (5) When deciding whether to make a direct payment in respect of a patient to a representative, a health body may, in particular, consider—
- (a) whether the patient has in the past, when the patient had capacity, expressed in writing, or by other means which are understandable, a wish for direct payments to be made to them or for their benefit;
 - (b) so far as reasonably ascertainable, the beliefs and values that would be likely to influence the patient's decision as to whether or not to consent to receive a direct payment if the patient had capacity; and
 - (c) any other factors that the patient would be likely to consider on the issue of whether to consent to receive a direct payment if the patient were able to do so, including the patient's wishes and feelings.
- (6) Before deciding whether to make a direct payment in respect of a patient to a nominee, a health body may—
- (a) consult the persons mentioned in paragraphs (2)(a) and (3)(a) to (c) and, where relevant, (e);
 - (b) require a patient with the necessary capacity or competence to provide information relating to the patient's state of health or any health condition in respect of which the direct payment is contemplated; and
 - (c) require the nominee to provide information relating to any bank, building society, post office or other account into which the direct payment may be made.
- (7) Before deciding whether to make a direct payment in respect of a patient to a nominee, a health body must—

(a) be satisfied that the nominee is capable of managing a direct payment by themselves or with the assistance that may be available to them;

(b) where the nominee is an individual, require the nominee to apply for an enhanced criminal record certificate issued under section 113B of the Police Act 1997 including suitability information relating to vulnerable adults under section 113BB of that Act, unless the nominee is an individual living in the same household as the patient, a family member mentioned in paragraph (8) or a friend involved in the provision of the patient's care; and

(c) where the nominee is a body corporate or an unincorporated body of persons, require that the individual whom the nominee has decided will, on behalf of the nominee, have overall responsibility for the day-to-day management of the patient's direct payments, applies for an enhanced criminal record certificate issued under section 113B of the Police Act 1997 including suitability information relating to vulnerable adults under section 113BB of that Act.

(8) The family members referred to in paragraph (7)(b) are—

(a) the spouse or civil partner of the patient;

(b) a person who lives with the patient as if their spouse or civil partner;

(c) a person who is the patient's—

(i) parent or parent-in-law,

(ii) son or daughter,

(iii) son-in-law or daughter-in law,

(iv) stepson or stepdaughter,

(v) brother or sister,

(vi) aunt or uncle, or

(vii) grandparent;

(d) the spouse or civil partner of any person specified in sub-paragraph (c); and

(e) a person who lives with any person specified in sub-paragraph (c) as if that person's spouse or civil partner.

(9) In deciding whether a patient, representative or nominee is capable of managing a direct payment, a health body may, in particular, consider whether—

(a) the patient, representative or nominee would be a suitable person to arrange with any person or body to provide, or assist in providing, any services secured by means of direct payments for the patient;

(b) the patient, representative or nominee has not been able to manage a direct payment or a direct payment to secure relevant services for social care under the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009; or

(c) the patient, representative or nominee is capable of taking all reasonable steps to prevent fraudulent use of the direct payment.

(10) If a health body considers making a direct payment to a patient in accordance with this regulation and decides not to make such a payment, they must inform the patient and any representative or nominee in writing of the decision, and state the reasons for the decision.

(11) Where a health body decides under paragraph (10) not to make a direct payment, a patient, representative or nominee may require the health body to re-consider the decision, and may provide evidence or relevant information for the health body to consider as part of that deliberation.

(12) A health body must inform the patient and any representative or nominee in writing of the decision on a re-consideration, and state the reasons for the decision.

(13) A health body may not be required to undertake more than one re-consideration following a decision under paragraph (10) in any six month period"

7.2 The wording of regulation 7 is not especially clear but it appears to set up a series of different decision-making processes, depending on whether the patient has capacity or is a child and whether a nominee is to be appointed or not. The structure is:

- a) The decision-making process in Regulations 7(2) and 7(9) applies where the patient is over the age of 16 and has capacity;
- b) The decision-making process in Regulations 7(3), 7(4), 7(5) and 7(9) applies where the patient is under the age of 16 and lacks capacity and a direct payment is being made to a representative;
- c) The decision-making process in Regulations 7(6), 7(7) and 7(9) applies where it is proposed that a nominee is to be appointed (irrespective as to whether the patient is an adult or child and whether the patient has capacity or not).

7.3 The Regulation thus sets up a series steps and tests that a health body is required to follow when making this decision-making process as to whether to set up a direct payment arrangement for a particular patient. The decision-making processes are subtly different depending on whether the patient has capacity or not, and whether a nominee is to be appointed or not. The health body would be well advised to keep proper records of the

decision-making process in order to be able to demonstrate that it has followed the process properly and thus has made a lawful decision (particularly if the eventual decision is to refuse to set up a direct payment arrangement).

7.4 **The Regulation 7 decision where the patient has capacity:** The NHS body with power to set up a direct payment is the NHS commissioner, not the existing provider of NHS services to the patient. The commissioner will know the nature of the services commissioned for the patient but may well be unaware of all of the details of the patient's medical condition. Accordingly, where a patient makes a request for a direct payment, the step is for the health body to collect information about the patient's medical condition so that it can understand the nature of the services that would be included in any direct payment arrangement. Regulation 7(2)(b) provides that the health body may require the patient to provide information to the health body relating to:

- a) the patient's state of health,
- b) any health condition of the patient in respect of which a direct payment is contemplated.

7.5 There are further provisions about the provision of personal data relating to the patient in Regulation 12 which provides:

“Any information that must be provided under these Regulations to a health body must be—

- (a) legible;
- (b) accompanied by the relevant authorisation enabling the taking of copies or making of extracts, where appropriate;
- (c) if so requested by a health body, accompanied by—
 - (i) an explanation by the information provider of anything which has been provided, or
 - (ii) a statement to the best of the knowledge and belief of the information provider as to where information or evidence that the person has failed to provide is held”

- 7.6 Regulation 12 only applies where the patient has capacity to make decisions to release data to the health body. The Regulations provides that a patient with capacity who seeks a direct payment arrangement is required to provide any relevant information sought by the health body, even though this is sensitive personal data relating to the patient under the Data Protection Act 1998 (“DPA”). In practice, much of the information that the patient or their representative will be called on to provide will be held by whoever presently provides services to the patient. This could be a GP, an HS community trust, an NHS acute trust, a care home or a domiciliary care provider. Thus, if a capacitous patient wishes to set up a direct payment arrangement, the patient is required to authorise those holding information about him or her to provide all relevant information about the patient’s medical condition to the health body that is thinking about setting up the direct payment.
- 7.7 Any information which is passed to the health body as a result of a request made under Regulation 7(3)(b) will be highly likely to be both “personal data” and “sensitive personal data” within the meaning of the DPA. Any data controller is entitled to rely on the explicit consent given by the patient to process the data by providing it to the health body. The health body is, in turn, entitled to use that data for the purpose of assisting it to make its own decisions about the direct payment. However health bodies are not, without more, entitled to share the data with any third party. The health body also needs to be careful to ensure that this data is not used for any other purpose because, in doing so, the health body may be contravening its obligations under the DPA.
- 7.8 It would be possible for the health body to seek “explicit consent” from the patient to the health body sharing data about the patient’s condition a limited range of other persons outside the health body as part of this decision-making process but the health body probably cannot insist that such consent is provided. The conditions which must be satisfied before sensitive personal data can be shared are set out at Schedules 1 to 3 DPA. Unless the health body both has explicit consent (or satisfies one of the other criteria in Schedule 3 DPA) and acts both fairly and lawfully, it will be unlawful for the health body to divulge any details of the patient’s medical condition to any third party.
- 7.9 **Information about a proposed bank account to be used for direct payments:** Regulation 7(2)(b)(iii) enables the health body to require the patient to provide information about any “any bank, building society, post office or other account into which a direct payment may be

made". Any such bank account must comply with the provisions set out in Regulation 10 which provides:

"(1) Where a health body has decided to make direct payments to or in respect of a patient, a health body must only make the payments into an account approved by the health body for the benefit of the patient if they are satisfied that the requirements in paragraphs (2), (3) and (5) are met.

(2) The account mentioned at paragraph (1) must be capable of—

(a) providing for monies paid into the account to be held only for the purposes of securing services by means of—

- (i) direct payments under these Regulations,
- (ii) direct payments to secure relevant services for social care,
- (iii) payments made by the Independent Living Fund (2006), or
- (iv) other payments to secure relevant services for a disabled person; and

(b) being audited (by reference to statements setting out the source of monies deposited and the destination of monies withdrawn) by—

- (i) a health body, or
- (ii) anyone authorised in writing by a health body.

(3) The account mentioned in paragraph (1) must be—

(a) accessible only by named persons approved by a health body; and

(b) used only to hold monies paid into the account by way of the payments mentioned in paragraph (2)(a).

(4) A health body may require a patient, representative or nominee to provide the health body with access to information about an account into which a direct payment is, or may be made.

(5) A health body must ensure that an account mentioned in paragraph (1) is subject to arrangements or procedures that the health body considers adequate to—

(a) enable the monitoring and review mentioned in regulation 14(1)(a) and (6)(c) to be carried out; and

(b) ensure that direct payments paid into it will be used only for services agreed in a patient's care plan.

(6) Paragraphs (1) to (5) do not apply where a patient is in receipt of a one-off direct payment"

- 7.10 The Regulations thus require a patient, their representative or any proposed nominee to set up a dedicated bank account to handle direct payments (and for the other purposes set out in Regulation 10(2)(a)). The bank account cannot be used for any other purpose and must be capable of being audited by the health body to ensure that the payments are used for their intended purposes. This bank account will exclusively handle public money and must be used solely to fund care services for the patient. Money paid under a direct payment becomes the property of the patient or representative once it is paid over by the health body, but the patient or representative comes under a series of statutory obligations in relation to the money. However the 2103 Regulations do not provide that the patient or their representative holds the money on trust for the purposes of the care plan. Thus any money paid over becomes the property of the patient or representative, albeit with the right of the health body to seek repayment in the circumstances set out below.
- 7.11 **Consultation by the health body:** The next step in setting up a direct payment for a patient with capacity is consultation with a series of individuals who may have legitimate perspectives on the wisdom of setting up a direct payment arrangement for a particular patient. The health body has a power (but not a duty) to consult those people listed in Regulation 7(2)(a). The categories of people who can be consulted is not closed because Regulation 7(2)(a)(viii) provides that the health body can consult *“any other person who appears to a health body to be able to provide information of relevance”*. The purpose of the consultation is to assist the health body make a decision *“whether to make a direct payment”* and in particular to make the decision set out in Regulation 7(2)(c) namely whether *“the patient is capable of managing a direct payment by themselves or with the assistance that may be available to them”*.
- 7.12 This consultation needs to be handled with care because, unless the health body has been provided with explicit consent by (or possibly on behalf of) the patient to disclose medical information about the patient to family members and others, the health body will have to be cautious about what information is disclosed about the patient to consultees during the consultation. The health body needs to disclose to consultees that the patient is seeking a direct payment and ask them whether, in their opinion, the patient (and any proposed representative) will be able to manage a direct payment and to invite the consultee to provide the health body with any information held by that person that may be relevant to the decisions that the health body has to take about setting up or operation of a direct payment

arrangement. However, as part of the process of seeking views, the health body must be careful to preserve the confidentiality in personal data relating to the patient. Those providing care to the patient may well know something about the patient's medical condition, but care must be taken not to disclose additional information relating to the patient's health as part of the consultation. There is no general right for family members to know the details of a medical condition suffered by another family member and, absent explicit consent, the health body may be acting in breach of its duty under the DPA if it makes disclosures as part of the consultation exercise.

- 7.13 The health body is not under an absolute duty to consult anyone listed in in Regulation 7(2)(a). But the existence of the power suggests that the health body ought carefully to consider carefully whether there is likely to be any benefit in seeking views from any person and, if so, ought to seek and record their views.
- 7.14 **Consideration of the proposed Care Plan with the patient:** The 2013 Regulations separate out the decision-making process as to whether a direct payment arrangement should be set up (Regulation 7) with Care Plan to be put in place once the direct payment is put in place (Regulation 8). In practice, it is difficult to see how the health body could properly follow the decision-making process under Regulation 7 unless it had started to develop a care plan and was thus able to discuss the risks of the direct payment arrangement with the patient. Until work on the care plan is commenced, the health body will not necessarily know whether the patient has the capacity to manage a direct payment arrangement. Both the health body and the patient need carefully to consider what would be involved in passing over responsibility for commissioning services to the patient. The statutory requirements relating to the Care Plan are set out below but, unless it becomes clear to the health body at an early stage that a direct payment arrangement is unsuitable, the Care Plan (including the discussion of the risks) will need to be developed and agreed with the patient before the Regulation 7 decision can be made. The health body will also need to agree the amount of direct payment with the patient (as to which see below) before any Regulation 7 decision can be made to go ahead with the direct payment arrangement .
- 7.15 **The capability question for a direct payment to a patient with capacity:** Once the health body has:

- a) collected relevant information about the capacitous patient,
- b) undertaken its consultations,
- c) developed a suitable care plan;
- d) discussed the risks and satisfied itself that the patient understands them and can take on those risks; and
- e) agreed the amount of the direct payment,

the health body has to address the question in Regulation 7(2)(c), namely whether it is satisfied that the patient is “*capable of managing a direct payment*”. The health body can reach this view by looking at the patient’s capacity together with the assistance that may be available to the patient.

7.16 At this stage of the decision-making process the health body also has the power (but not the duty) to address the additional factors in Regulation 7(9) as part of its overall assessment of the capability question. For a patient with capacity, these factors cover the following broad issues:

- a) Whether the patient (with or without assistance from a nominee or support organisation depending on the proposal) has the capability to manage the contracts needed to deliver care to the patient. In particular, the health body will need to consider whether the patient, with or without a nominee, has the ability to become an employer of his or her own care workers, to manage the rotas, make the required payments including PAYE and pension sums, and generally act as an appropriate employer;
- b) Whether the patient has been unable to manage a social care direct payment in the past and, if so, what is likely to be different this time?
- c) Whether the patient is capable of taking all reasonable steps to prevent fraudulent use of the direct payment. Direct payment monies are taxpayers money which are passed to the patient under arrangements which impose a statutory requirement on the patient to use the money for a particular purpose. The relatively high level of autonomy which is provided for patients means that there can be a substantial risk of fraud, and thus proper processes need to be put in place to prevent fraud. The health body needs

to ensure that it is satisfied that the patient is capable of taking all reasonable steps to prevent the money being used for fraudulent purposes before reaching the decision that the patient (with or without a nominee) is capable of managing a direct payment.

- 7.17 The health body therefore has to consider all of these factors as part of addressing the statutory test set up by Regulation 7(2)(c). It is essential for the decision maker to make a written record of the decision and the reasons for making this decision, whether the decision is to approve a direct payment or not.
- 7.18 If the health body decides that a patient with capacity is not capable of managing a direct payment by themselves, even with the assistance of such persons as the patient proposes (or someone else as a nominee that the health body proposes), that is the end of the decision-making process because no direct payment arrangement can lawfully be set up. The health body has no power to proceed to make a direct payment arrangement unless it is satisfied on the capability question. In making this decision, the health body has to take into account the information provided by the patient and on his or her behalf and the views expressed as part of its consultations. However, the health body has a wide margin for making a discretionary decision to decide whether it is or is not satisfied that the patient is capable of managing a direct payment by themselves or with the assistance of a nominee. A failure to give proper reasons would make the decision-making process unlawful: *R (Ermakov) v Westminster Council* [1966] 2 All ER 302 and *R (Oyston) v Parole Board & Ors* [2000] EWCA Crim 3552.
- 7.19 **The capability decision-making process for a child under the age of 16 or for a patient who lacks capacity:** The decision-making process in regulation 7(2) only relates to a decision to make a direct payment to a patient who is over the age of 16 and has capacity. If the patient is a child under the age of 16 or does not have capacity, the direct payment is made to either the representative or a nominee (if there is to be one) and not to the patient. The decision-making process the health body has to follow in this case leads up to the test in Regulation 7(4)(b) which is whether the health body is:

“satisfied that the representative is capable of managing a direct payment by themselves or with the assistance that may be available to them”

- 7.20 The stages to the process are similar to the stages for the patient with capacity, namely:

- a) Information gathering;
- b) Consultation;
- c) Development of the care plan and the risk;
- d) Financial proposals; and
- e) Capability decision, including by reference to the Regulation 7(9) factors.

7.21 Information gathering: Regulation 7 does not give the health body a specific power to require any third party to provide information to the health body about the patient's health conditions where the patient is under the age of 16 or lacks capacity. It follows that the proposed representative, nominee, or anyone else holding information about the patient, is under no legal duty to provide information to the health body in response to such a request. However, if the patient lacks capacity, any decision maker acting on behalf of the patient would be under a legal duty (pursuant to the MCA) to make disclosure decisions which are in the best interests of the patient. If a parent, care worker, doctor, nurse or any other person who held information about a patient was asked by a health body to provide information about a child patient or an adult who lacks capacity in order to assist a health body make a decision as to whether to set up a direct payment arrangement, that person would have to decide whether it was in the best interests of the patient to do so. If, for example, a CCG asked for relevant information about a young person with learning disabilities, it is hard to envisage any circumstances in which such a person would consider that it was not in the best interests of the patient not to provide the required information to the CCG. Provided appropriate confidentiality assurances were provided by the CCG, it would almost always be in the best interests of the patient to co-operate with the CCG in providing the information. If there was a dispute, that dispute could be referred to the High Court (for a child under the age of 16) or to the Court of Protection for adjudication.

7.22 Consultation where a representative is proposed: If it is proposed that a representative should be appointed, Regulation 7(3) provides a list of persons who the health body has a power to consult. Although the health body is not under an absolute duty to consult any of these individuals about the suitability and capability of the representative, the health body ought to do so if it considers that any of them may have information which will assist it in deciding if the suitability and capability of the representative. The list of people includes the patient. The procedural requirements of article 8 apply notwithstanding the patient has lost capacity and would almost certainly be breached if the health body did not consult a patient

who was capable of expressing a view on a change to their healthcare arrangements. The health body is not bound to act in accordance with any view expressed by a patient who lacks capacity, but is required to consider the patient's views as part of the decision-making process.

- 7.23 Regulation 7(4)(a) provides that the health body may require the representative to provide information relating to the bank account into which the direct payment will be made. The bank account must satisfy the Regulation 12 requirements (see paragraph 7.9 above).
- 7.24 There are another set of considerations which a health body is encouraged to consider before deciding that a representative is capable of managing a direct payment arrangement in Regulation 7(5). These revolve around the past and present wishes and feelings of the patient, along with the beliefs and values of the patient. Where the health body is making the decision whether to set up a direct payment arrangement for a patient who lacks capacity or a child, the health body has to act in the best interests of the patient. Section 4 MCA sets up a specific decision-making process that has to be followed by any best interests decision maker, including the health body when it is making this decision for anyone over the age of 16. A similar process must be followed by a health body which is acting in the best interests of a child under the age of 16. The factors set out in Regulation 7(5) are all factors that, where appropriate on the facts of an individual case, the health body needs to take into account in order to follow the section 4 MCA process.
- 7.25 **The capability question where a direct payment is proposed to be made to a representative:** Once the health body has:
- a) collected relevant information about the representative;
 - b) undertaken its consultations about the representative,
 - c) developed a suitable care plan in conjunction with the representative;
 - d) discussed the risks and satisfied itself that the representative understands them and can take on those risks; and
 - e) agreed the amount of the direct payment with the representative,

the health body has to address the question in Regulation 7(4)(b), namely whether it is satisfied that the representative is "capable of managing a direct payment". The health body

can reach this view by looking at the representative's capacity, together with the assistance that may be available to the representative.

- 7.26 At this stage of the decision-making process the health body also has the power (but not the duty) to address the additional factors in Regulation 7(9) as part of its overall assessment of the capability question. For a child patient or a patient who lacks capacity, these factors cover the following broad issues:
- a) Whether the representative (with or without assistance from a nominee or support organisation depending on the proposal) has the capability to manage the contracts needed to deliver care to the patient. In particular does the representative have the ability to become an employer of any care workers needed for the patient, to manage the rotas, make the required payments including PAYE and pension sums, and generally act as an appropriate employer;
 - b) Whether the representative has been unable to manage a social care direct payment in the past and, if so, what is likely to be different this time?
 - c) Whether the representative is capable of taking all reasonable steps to prevent fraudulent use of the direct payment.
- 7.27 The health body has to consider all of these factors as part of addressing the statutory test set up by Regulation 7(4)(b) concerning the capacity of the representative. It is thus essential for the decision maker to make a written record of the decision and the reasons for making this decision.
- 7.28 If the health body decides that a representative is not capable of managing a direct payment by themselves or with the assistance of such persons as the representative proposes, that is the end of the decision-making process because no direct payment arrangement can lawfully be set up. The health body must provide the patient and the representative with reasons for any decision to refuse to provide a direct payment.
- 7.29 **The capability test where a nominee is proposed:** A nominee can be proposed both in cases where the adult patient has capacity and, for a child or patient who lacks capacity, where a

representative is appointed. Regulation 7 provides for steps to be taken leading up to an additional capacity test for the nominee. The test is in Regulation 7(7)(a) namely that the health body is:

“satisfied that the nominee is capable of managing a direct payment by themselves or with the assistance that may be available to them”

7.30 The structure of the obligations is similar to the previous cases. It involves:

- a) Consultation with all the persons who can be consulted where a patient has capacity (i.e. those listed in Regulation 7(2)(a));
- b) Consultation with extra persons who have to be consulted where a representative is being considered (i.e. those listed in Regulation 7(3)(a) to (c));
- c) Provision of information about the proposed bank account to check that it satisfies Regulation 12.

7.31 Regulation 7(6)(b) provides that a health body can:

“require a patient with the necessary capacity or competence to provide information relating to the patient's state of health or any health condition in respect of which the direct payment is contemplated”

7.32 This is a slightly strangely worded provision since it contemplates a category of patients who do not have capacity to provide information about their own health conditions to a health body but who have the “competence” to do so. This may refer to individuals with borderline or fluctuating capacity, but is difficult to understand what the draftsman of the Regulations had in mind. A health body already has the right to seek this information from a patient with capacity under Regulation 7(2)(b) and so this additional power appears to add nothing. However, if the patient does not have capacity, the patient is not a lawful decision maker to decide whether to pass over this information. It is therefore unclear what this Regulation adds to the existing powers for the health body.

- 7.33 Regulation 7(7) provides that where a nominee is an individual, he or she must have to apply for an enhanced criminal record certificate issued, including suitability information relating to vulnerable adults. There is an exception to this requirement where a nominee is an individual living in the same household as the patient, a family member of the patient or a “friend” involved in the provision of the patient's care. The term “friend” is not defined but is presumably intended to differentiate an informal carer who had a relationship with the patient before the direct payment was set up from someone who is brought in to act as a nominee in order to help manage the direct payment arrangement (and is probably paid for doing so). If the nominee is a company then Regulation 7(7)(b) requires the individual with “overall responsibility for the day-to-day management of the patient's direct payments” to be approved.
- 7.34 If the health body decides not to approve the nominee and hence not to go ahead with a direct payment arrangement, the patient, any proposed representative and any proposed nominee must be informed and reasons for the decision must be given: see Regulation 7(10).

8 The Care Plan and the care Plan Co-ordinator.

- 8.1 Regulation 7(3) provides that the health body has to appoint a person to be a care co-ordinator whose functions are described above (see paragraph 5.12 above). Regulation 8(4) provides that the care plan must specify the following:

- “(a) the health needs to be met by services secured by means of direct payments, and the health outcomes intended to be achieved through the provision of the services;
- (b) the services to be secured by means of direct payments that the health body considers necessary to meet the health needs of the patient;
- (c) the amount to be paid by way direct payments, and the intervals at which monies are to be paid;
- (d) the name of the person who is the care co-ordinator in respect of the patient;
- (e) who is to be responsible for monitoring each health condition of the patient in respect of which direct payments may be made;
- (f) the anticipated date of the first review mentioned in regulation 14(2)(a) (monitoring and review of direct payments) and how it is intended to be carried out; and

(g) the period of notice that is to apply if, following a review under regulation 14(2)(a), a health body decides to reduce the amount of the direct payments or to stop making the direct payments.

8.2 The Guidance explains the role of the care plan as follows:

“5.1 Care Planning

89) The care plan is at the heart of a personal health budget. Drawing up of a care plan should involve a series of discussions between the person receiving the care, their nominee or representative, their care coordinator ... and the appropriate health and social care professionals involved in the individual’s care. The personal health budget toolkit includes information and examples that provide CCGs with additional information on care planning.

90) Wherever possible, CCGs should work with local authorities and other healthcare providers to ensure that the person has a single plan covering their health and wellbeing needs across both the NHS and social care. This could include all the services and support provided, whether traditionally commissioned or through notional or third party budgets, as well as direct payments. For children with special educational needs and disabilities, who have a single education, health and care plan, this could also include their educational needs.

91) The regulations and thus the use of the term ‘care plan’ in this guidance only applies to that part of a person’s care plan related to services purchased by direct payments for healthcare, although the principles are applicable to all ways of managing a personal health budget.

92) The care plan is an agreement between the CCG and the person receiving direct payments, and includes responsibilities on both sides. It is therefore vital that people are supported throughout the care planning process. This will help ensure that they are able to make informed decisions in their best interests, and that they do not find the process overly burdensome or overwhelming. This support could take many forms - it may be from their healthcare professional, but some people may prefer an independent person to guide them through the process and liaise with the relevant parties. As with each aspect of personal health budgets, the best approach is to enable choice and not assume that the same option suits everyone. The personal health budget toolkit contains information and examples which will help CCGs and others consider the best ways for supporting their local population.

93) As a result of the care planning discussion, the care plan should clearly set out the health needs that the direct payment is to address. These may be reasonably broad, but it should be clear to both the CCG and the people involved what the direct payments are meant to achieve.

94) Having set out the health needs, the care plan should also set out the outcomes that are intended to be achieved. These may relate to both health and 'wellbeing' outcomes.

CCGs have broad powers to address people's health and wellbeing needs, and a good care plan should address people's needs holistically.

95) Having set out the health needs and the intended outcomes, the care plan must specify the services to be secured by the direct payment in order to achieve these. This should be done in such a way to enable the CCG to be satisfied that the health needs and identified outcomes are likely to be met.

96) The CCG must make arrangements for the person, their representative or nominee to obtain information, advice or support in connection with the direct payments. These arrangements should be specified in the care plan and could be a service for which direct payments may be made”

8.3 The NHS England published materials include a useful handbook⁷ on care planning for people with long-term conditions.

8.4 There is no requirement that a care plan has to propose funding for every service that a disabled person might have a need or which the patient may find helpful. The primary duty on NHS bodies is to provide services to meet the “*reasonable requirements*” of a patient: see section 3(1) of the NHS Act 2006. The courts have repeatedly said that NHS commissioners are entitled to take the available budget into account in deciding what services it is reasonable for the NHS to provide. More details on this subject are set out in the chapter on commissioning and priority setting. However health bodies should be careful to ensure that the care planning process provides patients with an equivalent level of service under a direct payment as can be secured by services that are directly commissioned. Any marked differential in levels of service could give rise to indirect discrimination claims.

8.5 Regulation 8 provides that the services described in the care plan should be those which the health body “considers necessary to meet the health needs of the patient”. The reference in Regulation 8 to “health needs” must mean the same as “reasonable requirements” in section 3(1) NHS Act.

9 **Setting the budget for direct payments.**

9.1 Having described the services to be provided in the care plan, the health body then has to set the budget. Regulation 13 of the 2013 Regulations provides:

⁷ See <https://www.england.nhs.uk/wp-content/uploads/2016/04/core-info-care-support-planning-1.pdf>

“13.—(1) A health body must ensure that the amount of the direct payments paid to or in respect of a patient is sufficient to provide for the full cost of each of the services specified in the care plan.

(2) Where a health body is notified, or becomes aware, that the state of health of the patient has changed significantly, but in the view of the health body a review mentioned in regulation 14 is not necessary, the health body must be satisfied that the amount of the direct payments continues to be sufficient in accordance with paragraph (1).

(3) A health body may at any time increase or reduce the amount of the direct payments if satisfied that the new amount is sufficient in accordance with paragraph (1).

(4) A health body may reduce the amount paid by way of direct payments by an amount not exceeding the amount due in respect of a period for which payment falls to be made where—

- (a) direct payments have been accumulated and remain unused; and
- (b) the health body considers that it is reasonable to offset the monies accumulated against the outstanding amount to be paid for that period.

(5) Where a health body decides to reduce the amount of the direct payments, the health body must provide reasonable notice in writing to the patient, representative or nominee stating the reasons for the decision”

9.2 The 2013 Regulations thus impose a requirement that the direct payment must be sufficient to meet the cost of all of the services set out in the care plan. This means that the CCG must satisfy itself that the patient, or those making decisions on behalf of the patient, is provided with sufficient money so that he or she will actually be able to purchase services to meet the needs set out in the care plan. Thus, by way of example, if the care plan includes the cost of a carer or a nurse for 20 hours per week, the health body needs to be satisfied that the direct payment will meet the full cost of employing one or more staff to provide those services. The direct payment will thus need to cover:

- a) Wages;
- b) National insurance payments;
- c) Pension payments;
- d) Recruitment costs;
- e) Training costs;
- f) Insurance costs;
- g) Any consumables that the member of staff will use;

- h) The administration of costs associated with employing staff; and
- i) Any other employment costs that will arise in a particular case.

9.3 The breath of the costs that must be included in the budgeting is set out in the Guidance which provides:

“117) Direct payments must be set at a level sufficient to cover the full cost of each of the services agreed in the care plan.

118) When calculating the budget, CCGs should ensure that they recognise the additional ‘hidden’ costs. For example, if someone is employing an assistant, they must ensure that there is sufficient funding available to cover the additional necessary costs of employment such as tax, National Insurance, training and development, pension contributions, any necessary insurance such as public liability, emergency cover and so on.

119) Direct payments must cover the full cost of the care agreed in the care plan. However, they do not circumvent existing Government policy around additional private care. In no circumstances should the budget be set at a level where someone is expected to pay for care privately in order to meet their agreed health needs. If someone wishes to purchase additional care privately, they may do so, so long as it is additional to their assessed needs, and it is a separate episode of care, with clearly separate lines of clinical accountability and governance.

120) If the amount of a direct payment is not set at a suitable level, it must be reviewed and adjusted.

121) CCGs may wish to consider including a contingency fund in the direct payment, either for the individual or as part of a collective risk pool, to ensure that the budget is available to fully fund the care plan.

122) The personal health budget toolkit contains two budget setting documents which set out the learning from the pilot programme - one focuses on budget setting in NHS Continuing Healthcare and the other explores different methods used by pilot sites to set budgets beyond NHS Continuing Healthcare”

9.4 There is limited publicly accessible guidance on how health bodies should set budgets. In November 2012 the Department of Health published “Personal Health Budgets Guide - How to set budgets – early learning”⁸. However, the Guidance is of marginal benefit as it only describes a series of methods that different PCTs developed within the pilot without providing enough details to be of any real benefit to either patients or commissioners.

⁸ See

http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/Toolkit/HowPHBwork/SettingBudget/Phb_guide_HowToSetBudgets.pdf

9.5 Some CCGs and local authorities have developed “Resource Allocation Systems” (“RAS”) for setting the amounts of a direct payment. An RAS can be a useful tool for a CCG to work out the cost of the direct payment, provided the figures used to populate the RAS are realistic. Hence, for example, if a patient has a need for 20 hours of carer support at home, the care plan may suggest that the patient employs one or more carers to fulfil this role. The RAS can be helpful in setting the likely cost of employing a suitably trained carer and calculating the additional costs needed on top of wages. However, these costs need to be realistic costs that reflect the true costs employing the relevant service. The RAS cannot be moderated to reflect the amount of money that the health body is prepared to make available to support a service or the amount it considers it can afford.

10 The operation of a Direct Payment Arrangement.

10.1 Once a direct payment arrangement has been set up, payments will be made to the nominated bank account. Those payments must be used by the patient to purchase goods and services, as set out in the care plan. This is set out in Regulation 11(1) of the 2013 Regulations which provides:

“A patient, representative or nominee must—

- (a) use the direct payments to procure services specified in the care plan;
- (b) only use the direct payments in accordance with the patient's care plan, in particular, to secure the provision of the whole of the services specified in the care plan”

10.2 There are 2 duties imposed by this Regulation, the first is a positive duty and the second is a prohibition. The positive duty is under a combination of Regulation 11(1)(a) and the second half of the wording of Regulation 11(1)(b). This wording requires the patient or representative to use the money provided by the NHS to “*procure services specified in the care plan*” and to “*secure the provision of the whole of the services so specified*”. Even though the patient is a consultee concerning the care plan, responsibility for writing the care plan lies on the health body, not the patient. However once the care plan is written, the Regulations require the patient (or representative) to agree that he or she will procure services precisely in accordance with the care plan. Thus, if the care plan states that the patient will have 20 hours care worker support a week, the patient or representative takes on a legal duty to procure 20 hours care support for the patient every week. The normal rule in healthcare is

that the NHS has the duty to offer services to an NHS patient, but the patient has the right to accept or refuse the services. However, it is different for a patient who signs up to a direct payment arrangement because the Regulations impose a positive duty on the patient (or the representative) to accept the whole range of services set out in the care plan.

- 10.3 The second part of the Regulation 11(1) duty is a negative duty. The patient agrees that he or she will only use the direct payment money for procuring services in accordance with the care plan. This constitutes a legal bar on using the money provided by direct payment to fund any form of care for the patient or any benefit for the patient which is not set out in the care plan. This Regulation removes any freedom for patients or their representative to use direct payment money in the way the patient or the representative considers most beneficial for the individual patient, save to the extent that these decisions are supported by the health body as part of the care plan. The wording of this Regulation thus cuts across the freedom that a direct payment is supposed to give to the patient.
- 10.4 In practice, patients have a greater degree of freedom than the 2013 Regulations suggest because CCGs appear not to enforce their rights to re-charge patients if direct payment monies are used to procure services which are of benefit to the patient but are not precisely in accordance with the care plan. However, the strict legal position under the 2013 Regulations is that a tight legal duty is imposed on the patient or representative to use the money provided to procure all of services set out in the plan and not to use a single penny to procure any other type of service.
- 10.5 The remainder of Regulation 11 of the 2013 Regulations covers a variety of requirements to ensure that direct payment money is used appropriately. These are:
- a) Regulation 11(2)(a)(i) requires any provider who is carrying out a “regulated activity” under the Regulation 3 and Schedule 1 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 is required to be registered with the Care Quality Commission. This provision does not apply to individual care staff who are employed by the patient but will apply where staff are employed by a domiciliary care agency. It is the agency which carries out the regulated activity and thus needs to be registered;

- b) Regulation 11(2)(a)(ii) provides that the patient must ascertain that any individual providing services to the patient is registered with the relevant professional body. Hence, for example, the patient must check to ensure that any nurses employed or engaged in providing services must be registered with the Nursing and Midwifery Council and physiotherapists are registered with the Health and Care Professions Council;
 - c) Regulation 11(2)(a)(iii) is about professional indemnity insurance. It requires the patient to find out whether a provider is under a legal duty to maintain appropriate professional indemnity insurance.
- 10.6 Regulation 11(3) allows the patient or a representative to ask the health body to carry out the checks required under Regulation 11(2). Hence, in the usual case, the patient can ask the CCG to find out the regulatory status of an provider and whether any provider has appropriate insurance.
- 11 Monitoring and reporting on changes in the health of the patient.**
- 11.1 The care plan is only appropriate for a patient if it is up to date. A patient who has an improving, fluctuating or deteriorating condition may well find that the support set out in a care plan becomes out of date because it either provides too much or, more likely, too little support as the patient's medical condition changes. The health body has a duty under Regulation 14 of the 2103 Regulations to monitor the making of direct payments and the *"health conditions of the patient in respect of which direct payments are made"*. In addition to the duty of regular monitoring, the health body has a duty to conduct a review at appropriate intervals which must be at least:
- a) Within the first 3 months after the direct payment arrangement is set up; and
 - b) Annually thereafter (see Regulation 14(2)).
- 11.2 A patient can request a review and, if a request is made, the health body has a duty to consider whether to carry out a review: see Regulation 14(7). The health body is not required to carry out a review on every occasion on which a request is made. However, if the

patient or a representative provides information which suggests that the direct payment is insufficient to purchase sufficient services to meet the patient's reasonable needs, the health body probably has a duty to carry out a review in order to determine whether the care plan and budget properly meets the patient's reasonable needs.

11.3 The relevant information about the patient will be held by the patient and those caring for him and not by the CCG or NHS England. Although this is patient sensitive personal data and is legally confidential information, the patient has a duty to provide any information that the health body requests about:

- a) the state of health or any condition of the patient in respect of which the direct payment is made; or
- b) the health outcomes expected from the provision of any service: see Regulation 11(4).

11.4 There is a specific duty to consider carrying out a review if the health body becomes aware that the state of health of the patient has changed significantly: see Regulation 14(3). A health body is not required to carry out a review on every occasion where there is a significant change, but has a duty to consider whether to do so. In contrast, there is a duty to carry out a review if the health body "becomes aware" that the direct payments have not been sufficient to secure the services specified in the care plan: see Regulation 14(4). This duty may arise where the patient's health means that he or she has a greater need for services. However it can also arise if the health body is aware that local factors mean that the patient cannot, in practice, purchase the services he or she needs for the sum of money provided by direct payments. Hence, if the care plan and budget is based on a cost of employing a care worker for £X per hour, but the local market conditions mean that care workers cannot be employed on a secure basis at a cost of less than £Y per hour, the health body has the duty to carry out a review and will be obliged to increase the budget to meet the real cost of employing a care worker.

11.5 Regulation 14(5) sets out the matters that the health body is required to consider as part of a review. As part of every review the health body must:

- (a) review the care plan to establish whether it continues to provide appropriately for the health needs of the patient;
- (b) consider whether the direct payments have been used effectively;
- (c) consider whether the amount of the direct payments paid to or in respect of the patient is sufficient to provide for the full cost of each of the services specified in the care plan; and
- (d) consider whether the patient, representative or nominee has complied with the obligations imposed on them by or under regulation 11.

11.6 Regulation 14(6) sets out a series of steps that health body may take as part of a review (but which are not required to be part of every review). These steps are:

- “(a) re-assess the health needs of the patient for services to be secured by way of direct payments;
- (b) consult any of the persons mentioned in regulation 7(2)(a) or (3)(a) to (c) or, where relevant, (e) (consultation by a health body in relation to a decision to make a direct payment to or in respect of a patient);
- (c) review receipts, bank statements or other information relating to the use of the direct payments;
- (d) consider whether the direct payments have been effectively managed, including whether any provider of services secured by means of the direct payments—
 - (i) if carrying on a regulated activity, is registered as a service provider in respect of that activity with the Care Quality Commission,
 - (ii) has complied with any obligation that the provider has to be registered as a member of a profession regulated by a body mentioned in section 25(3) of the 2002 Act, or
 - (iii) operates under insurance or indemnity cover which is proportionate to the risks involved in providing the service and otherwise appropriate in relation to the services provided to the patient”

11.7 The actions that a health body can take following a review are set out in Regulation 14(8) as follows:

“(8) Following a review, a health body may, having regard to the purposes of the care plan and the consultations and enquiries under regulation 7—

- (a) amend the care plan;
- (b) substitute the patient for the nominee or representative of the patient, or substitute a representative or nominee for the patient, as the person to whom the direct payments are made;
- (c) increase, maintain or reduce the amount of the direct payments;
- (d) impose on the patient, representative or nominee either or both of the following conditions in connection with the making of direct payments—
 - (i) the recipient, whether the patient, their representative or their nominee, must not secure a service from a particular person, or
 - (ii) the patient, their representative or their nominee must provide information that the health body considers necessary other than as described at regulation 7(2)(b), (4)(a) or (6)(c) (information that can be required in relation to a decision to make a direct payment) or regulation 11(4), (7) or (8)(b) (conditions relating to information that are to be complied with by the patient, representative or nominee); or
- (e) take other action that the health body considers appropriate”

11.8 The health body has wide powers to act following a review. These powers include making changes to the care plan, changes to the amount of direct payments and changing the decision maker. The health body could decide that a particular care worker or agency should not be employed and paid for under direct payments including, for example, a family member who appears to be failing to provide appropriate care to the patient. The final general power allows the health body to take such other action in relation to the direct payment arrangement as the health body considers appropriate.

11.9 There are, however, probably three restrictions on the types of action that a health body can take under this Regulation. First, there are specific conditions under Regulation 17 that must be satisfied before the health body can take the decision to stop the direct payments. Hence, any decision to stop the direct payments altogether ought to be exercising the powers under Regulation 17 and not by the exercise of the general power under Regulation 14(8)(e). Secondly, the range of actions that the health body can lawfully take under Regulation 14(8)(e) is limited to actions of the same kind as the actions listed in Regulations 14(8)(a) to (d) as a result of the *ejusdem generis* rule. Thirdly, the health body can only use this power to take actions which promote the overall purpose of the health service and the management of

direct payments in particular, and must respect the human rights of the patient. Hence if, for example, the health body considers that the patient's health would be likely to improve significantly if the patient consented to have a particular surgical operation or agreed to take a particular pharmaceutical drug, the powers under Regulation 14(8) could not be used to require the patient to undergo that procedure even if the result would be an improvement in the patient's health and hence a reduction in the level of the direct payment.

11.10 If the health body decides to stop the direct payments after a review (by exercising the Regulation 17 powers) or to reduce the direct payments, the health body is required to give the patient or a representative written reasons for its decision: see Regulation 14(9). The patient can respond to the decision to stop or reduce direct payments by requiring the health body to carry out a further review: see Regulation 14(10). Although there is no express requirement in the 2013 Regulations to have any such review carried out by a different person to the original decision maker, there is a strong argument that the duty to carry out a "review" could only be validly discharged in practice by having a different decision maker looking at the case. Thus, when asked to review a decision, health bodies will protect their own positions by setting up systems to ensure that any review under the 2013 Regulations is carried out by someone other than the original decision maker.

11.11 The health body must give reasons for the outcome of a further review (see Regulation 14(11)) but if that review decides to uphold the decision, there is no right for the patient to request a third review (see Regulation 14(12)).

12 Decisions to reduce or stop direct payments

12.1 A direct payment arrangement may seem a good idea to a patient or those who care for a patient but these arrangements do not always work out well in practice. The patient or the representative takes on considerable administrative responsibilities and some patients find that the burdens of taking on the arrangements do not justify the benefits that the arrangements provide. Equally, a health body has to ensure that the public money which is provided under a direct payment arrangement is being used properly and that there is a sufficient level of accountability in the arrangements. The health body also needs to be confident that appropriate clinical governance is being maintained, particularly where the decisions are being made for the patient by a representative. Hence a decision to terminate a

direct payment arrangement can come from either the patient (or representative) or the health body.

12.2 The health body has the power to reduce the direct payment if the circumstances come within under Regulation 13(4) of the 2013 Regulations. This provides:

“A health body may reduce the amount paid by way of direct payments by an amount not exceeding the amount due in respect of a period for which payment falls to be made where—

- (a) direct payments have been accumulated and remain unused; and
- (b) the health body considers that it is reasonable to offset the monies accumulated against the outstanding amount to be paid for that period”

Where a health body decides to reduce the direct payment for a period it must give a written notice to the patient or representative setting out its reasons for taking this decision.

12.3 The health body has powers to stop a direct payment arrangement under Regulation 17. Regulation 17(1) provides that the health body must stop the direct payment arrangement if:

- a) The patient (other than a child under the age of 16) has capacity and withdraws his or her consent to the direct payment arrangement;
- b) The representative withdraws consent and there is no other representative who can consent to replace the existing representative;
- c) The child reaches the age of 16 and does not consent to the direct payment arrangement continuing (see Regulation 4(4)(b) and Regulation 17(1)(c)); or
- d) The patient lacked capacity when the direct payment arrangement was set up but has now regained capacity and not consent to the direct payment arrangement continuing (see Regulation 5(8)(b) and Regulation 17(1)(c)).

12.4 Regulation 17 does not specifically provide that a health body is required to stop a direct payment arrangement if the patient comes within the categories of persons who cannot have a direct payment, as listed in the Schedule to the Regulations. However Regulation 3(3)(c)

provides that direct payments may not be made to a person who is within the category of persons set out in the Schedule (see paragraph 2 above for details of the excluded persons). Thus, once a person comes within the category of persons in the Schedule the health body has no vires to continue the direct payment arrangement and must cancel it. The health body is also required to cease to operate a direct payment arrangement with a representative who comes within the terms of the Schedule because there is no vires to continue to operate direct payments with that person as a representative: see Regulation 4(1)(b) and 5(1)(b).

12.5 Regulation 17(2) gives a health body a general power to stop the direct payment arrangement and sets out a number of circumstances in which a health body may wish to consider whether to do so. It provides:

“A health body may stop making direct payments if satisfied that it is appropriate to do so and in particular if—

- (a) a person in respect of whom a direct payment is made is not a patient;
- (b) the health body does not consider that the representative or nominee is a suitable person to receive direct payments in respect of the patient;
- (c) the nominee does not agree to receive the direct payments in respect of the patient;
- (d) the person who has nominated the nominee pursuant to regulation 6(1) (nominated person) has withdrawn the nomination;
- (e) the direct payments have been used otherwise than for a service specified in the care plan;
- (f) the health body considers that theft, fraud or another offence may have occurred in connection with the direct payments;
- (g) the health body considers that the health needs of the patient cannot be, or are not being, met by services secured by means of direct payments; or
- (h) the patient has died”

12.6 The health body has a duty to give reasons to the patient or their representative when a direct payment arrangement is stopped: see Regulation 17(3). Notice must be given to the personal representative if the patient dies, although it is not clear to whom notice must be given if the patient dies intestate and no personal representative is appointed. The patient or

representative has the same rights to seek a reconsideration as when payments are reduced (see paragraph 11.10 above).

- 12.7 When a decision is taken to stop payments, the health body is required to give “reasonable notice” before the decision takes effect: see Regulation 17(8). The period of notice will depend on the circumstances and the reasons for the decision to stop the direct payments. However the Guidance notes as follows:

“In some cases, it may be necessary to stop the direct payment immediately, for example if fraud or theft has occurred. In these cases, ‘reasonable notice’ may include immediate termination of the direct payment. In these circumstances, the CCG should endeavor (*sic*) to protect public money as far as possible, whilst being mindful that they are still under a duty to provide healthcare if the individual requires it. No person should ever be denied the care they need. Where possible, CCGs should also endeavour to continue to provide a personalised service and maintain a continuity of care. For example, an independent user trust could be established to manage the budget or the CCG could directly commission the services agreed in the care plan”

- 12.8 Regulations 17(9) and (10) execute a formal assignment of contractual and employment liabilities from the patient to the health body at the point that a direct payment arrangement is brought to an end. These Regulations provide:

“(9) Any right or liability of the patient, personal representatives, representative or nominee in respect of or to a third party, acquired or incurred in respect of a service secured by means of a direct payment, shall transfer to a health body when the health body stops making direct payments pursuant to paragraph (1) or (2).

(10) The transfer of any liability under paragraph (9) is binding on the third party, even though, apart from this paragraph, it would have required the consent or concurrence of that party”

- 12.9 Thus any person who is employed by the patient under a direct payment becomes an employee of the health body at the point that a direct payment arrangement ceases. Equally any contracts to which the patient was a party transfer to the health body. Unwinding a direct payment arrangement could thus give rise to some difficult decisions for health bodies because, for example, a health body would need to consider whether there was any suitable alternative employment available for an employee before making a care worker redundant. That could lead to a duty on the health body to offer an employee work to support another patient before an employee could be fairly dismissed. Equally, the health body is required to take over the contractual liability liable under contracts with domiciliary care agencies or

other providers even though the health body never signed up to those contracts in the first place.

12.10 It is slightly strange that the health body only has a power but not a duty to stop the direct payment arrangement if the patient dies. The death of the patient will, of course, mean that the patient no longer has any health needs and thus has no need for services. However unwinding the employment and support arrangements which had been set up for the patient may incur some costs and take some time. The health body probably has a power but not a duty to bring the direct payment arrangement to an immediate end so as to allow it to continue the arrangement with a representative for a short period so as to allow contracts to be terminated and employees to be made redundant whilst the direct payment arrangement remains operative. That would prevent any contractual or employment liabilities being transferred to the health body. However, save to the extent needed to wind up the arrangements, the health body has no vires to continue the arrangement after the death of the patient and so should terminate the arrangements as quickly as possible.

12.11 One of the main circumstances in which a direct payment in practice is stopped in practice is when a patient with a chronic condition moves from his or her home into full-time care in a hospital, care home or other institution. In such a case, the justification for the direct payment no longer exists and the direct payment arrangement will usually come to an end (as opposed to being used to pay the care home fees

13 When can a health body seek repayment of direct payments?

13.1 The Regulations give wide powers to the health body to seek repayment of monies which have been paid to a patient or their representative. There is a general power in Regulation 15(1) to seek repayment in the following terms:

“A health body may require that part or all of a direct payment must be repaid to the health body, if satisfied that it is appropriate to require repayment having regard in particular to whether—

- (a) the care plan has changed substantially;
- (b) the patient’s circumstances have changed substantially;

- (c) a substantial proportion of the direct payments received by a patient, representative or nominee have not been used to secure services specified in the care plan and have accumulated;
- (d) the direct payments have been used otherwise than for a service specified in the care plan;
- (e) theft, fraud or another offence may have occurred in connection with the direct payments; or
- (f) the patient has died”

13.2 These wide powers appear to give the health body the right to make the decision that money should be repaid even the direct payment money has been used to employ care workers to provide services to the patient in accordance with the care plan. The only absolute condition that needs to be satisfied before a repayment claim can be made is that the health body is satisfied that it is “appropriate” that all or part of a direct payment should be repaid. However the Guidance suggests this power should be used more sparingly. At paragraphs 138 to 141 it states:

“138) CCGs should be aware that genuine errors can occur. The power to reclaim direct payments should not be used to penalise people for making mistakes or when the individual has been the victim of fraud.

139) If a substantial amount of money accumulates in the individual’s account due to an underspend for any reason, the CCG should consider whether it is appropriate to reclaim that money. In some circumstances, it may be more appropriate to simply reduce subsequent direct payments, factoring in the existing surplus. CCGs should also assess the reasons for the build up of the surplus as part of the review process – either the individual is not receiving the care they need or too much money was allocated.

140) When reclaiming money from someone with a representative or nominee, the CCG should approach the person holding the money, rather than the individual receiving care. The CCG should also ensure that, as far as possible, the person receiving care is also aware of their intention, and the reasons for this.

141) When reclaiming money from the estate of someone who has died, the CCG must approach the personal representatives of the individual to seek repayment. They should do so sensitively, and may wish to leave a period of grace to allow the executors of the will to ensure the estate is in order. The CCG should bear in mind that if the person, their representative or nominee was an employer, their employees will have employment rights, which may include a paid period of notice or redundancy payment”

13.3 This seems sensible guidance, with the possible exception of the guidance in paragraph 141 which does not appear to have taken account of the effect of the transfer of rights and liabilities under Regulation 17(9). Employees of the patient become employees of the health

body on the stopping of the direct payment arrangement and thus, following the stopping of a direct payment arrangement, any redundancy notices should be given by the health body and not the patient's estate (unless the health body continues the direct payment to the extent necessary to allow the estate to wind up these arrangements).

13.4 A health body must comply with the procedural requirements set out at Regulation 15(2) of the 2013 Regulations when making a decision to seek repayment. This Regulation provides:

“Where a health body decides under paragraph (1) that a sum must be repaid, the health body must give reasonable notice in writing to the patient and any representative or nominee, stating—

- (a) the reasons for the decision;
- (b) the amount to be repaid;
- (c) the time within which the sum must be repaid; and
- (d) the person who must repay”

13.5 The person who is required to make the repayment is entitled to ask for a review under Regulation 15 in the same way as a review can be sought if the amount of the direct payment is reduced or the direct payment is stopped. A health body should arrange for the decision maker who conducts the review to be a different person to the original decision maker or there is probably no proper compliance with the duty to carry out a review.

13.6 The Regulations give an express power to the health body to waive any requirement that a sum be repaid: see Regulation 15(7). This power can only be exercised after a decision has been made to seek repayment (whether communicated to the patient or not). Hence, if a patient or representative asks the health body to exercise this power, the health body has a duty to do so and must consider whether to waive a repayment or not to do so. If the health body informs the patient or a representative that it has made a decision to waive a repayment, it would face considerable legal difficulties in attempting to reverse that decision because the statement that the repayment claim was being waived may well have given rise to a legitimate expectation that no repayment would be sought, and that legitimate expectation could be enforced by the patient or representative.

13.7 Where monies are owing by the patient or representative, and the health body considers that there may have been theft, fraud or any other criminal offence, it is entitled to take summary proceedings to enforce this right to collect monies it has decided to reclaim. This right is set out at Regulation 16 of the 2013 Regulations which provides:

“(1) Where a sum must be repaid to a health body pursuant to regulation 15 and the reasons for the decision to require repayment is that theft, fraud or another offence may have occurred in connection with a direct payment, that sum may be recovered summarily as a civil debt.

(2) Paragraph (1) does not affect any other method of recovery”

13.8 It follows that there are 2 different means open to a health body which seeks to recover monies paid under a direct payment arrangement. First, if the reason for the repayment demand is that there may have been “theft, fraud or another offence”, the health body has the right to recover the sum summarily. It is not necessary for the health body to provide that there has, fact been, any theft, fraud or another offence. It is only necessary for the health body to show:

- a) there may have been theft, fraud or another offence; and
- b) this was the reason why the health body made the decision to issue a recovery notice.

13.9 The procedure for summary recovery is set out at section 58(1) of the Magistrates Court Act 1980 which provides:

“A magistrates' court shall have power to make an order on complaint for the payment of any money recoverable summarily as a civil debt”

13.10 Once the Magistrates Court have made an order that the health body recovers a specified sum, the sum is payable pursuant to the terms of the order made by the Magistrates Court. Once the order is made there are a variety of enforcement methods available to the health body.

13.11 In any case where the reason for the repayment demand is not there may have been theft, fraud or another offence, or where the health body elects not to use the summary procedure route, the health body has the right to issue debt proceedings in the County Court. Although

this is untested territory, it is probable that a person against whom proceedings are issued has the right to challenge the lawfulness of the decision (on public law grounds) to require the repayment. Hence there could be a “judicial review” trial of the reasonableness or other alleged unlawfulness of the decision to impose the payment in the County Court: see *Wandsworth LBC v Winder (No 1)* [1984] UKHL 2.

14 Direct Payments rules for patients in receipt of NHS Continuing Healthcare or Continuing Care for Children

14.1 The categories of patients who are eligible for NHS Continuing Healthcare or Continuing Care for Children are discussed elsewhere. However, there are special rules relating to direct payments and the management of budgets for any patients who are eligible for NHS Continuing Healthcare or Continuing Care for Children. There are subtle legal differences between the direct payment rights for patients who are eligible for NHS Continuing Healthcare or Continuing Care for Children and the legal rights of all other patients. It is too early to tell whether these will make any difference in practice but it seems unlikely that they will have any real impact.

14.2 The rules for eligible for patients who are eligible for NHS Continuing Healthcare or Continuing Care for Children are set out in Regulation 32B of the 2012 Regulations. This Regulation, which took effect from 1 April 2014, provides:

“(1) A relevant body must ensure that it is able to arrange for the provision of a relevant health service to an eligible person by means of a personal health budget which is managed in accordance with paragraph (2).

(2) A personal health budget must be managed in at least one of the following ways—

(a) the making of a direct payment;

(b) the application of the personal health budget by the relevant body in accordance with the outcome of discussions with the eligible person or that person's representative as to how best to secure the provision of the relevant health service to the person; or

(c) the transfer of the personal health budget by a relevant body to a person who applies the money in accordance with the outcome of discussions with the eligible person or that person's representative as to how best, with the agreement of the relevant body, to secure the provision of the relevant health service to the eligible person.

- (3) A relevant body must—
 - (a) publicise and promote the availability of personal health budgets to eligible persons and their representatives; and
 - (b) provide information, advice and other support to eligible persons and their representatives to assist them in deciding whether to request a personal health budget in respect of a relevant health service.
- (4) A relevant body must—
 - (a) give due consideration to a request made by or on behalf of an eligible person for a personal health budget;
 - (b) decide whether it is appropriate in the circumstances of the eligible person's case to arrange for the provision of the relevant health service to that person by means of a personal health budget; and
 - (c) if it decides that it would be appropriate, decide which of the ways mentioned in paragraph (2) would be the most appropriate way in which to manage the personal health budget.
- (5) A relevant body must make arrangements for eligible persons for whom a personal health budget has been arranged, and their representatives, to obtain information, advice and other support in connection with the management of the personal health budget.
- (6) The duty in paragraph (5) does not apply in relation to any part of a personal health budget to which regulation 9 of the National Health Service (Direct Payments) Regulations 2013 (information, advice and other support) applies.
- (7) If a relevant body decides to refuse a request for a personal health budget made by or on behalf of an eligible person, it must provide that person and their representatives with the reasons for that decision in writing.
- (8) On receipt of written reasons in accordance with paragraph (7), an eligible person or a person acting on the eligible person's behalf may require a relevant body to undertake a review of the decision and may provide evidence or information for the relevant body to consider as part of that review.
- (9) A relevant body must inform the eligible person or their representatives in writing of the decision following a review, and state the reasons for the decision.
- (10) A relevant body may not be required to undertake more than one review following a decision under paragraph (7) in any six month period”.

14.3 In September 2014, NHS England issued guidance about Regulation 32B of the 2012 Regulations called “*Guidance on the “right to have” a Personal Health Budget in Adult NHS*”

*Continuing Care Healthcare and Children and Young People's Continuing Care*⁹". Whilst the Guidance speaks of a "right" to a personal health budget, a close examination of the Regulation shows that an eligible patient does not have any legal rights to a health budget. Regulation 32A(1) provides that the health body (i.e. a CCG or NHS England) has to ensure that it is able to arrange for the provision of a relevant health service to an eligible person by means of a personal health budget which is managed in accordance with paragraph (2). Hence, the Regulation imposes a duty on the CCG and NHS England to have decision-making systems in place to ensure that it is able to offer a health budget by any of the means set out at Regulation 32A(2). It does not provide that a patient who is eligible for NHS Continuing Healthcare or Continuing Care for Children has a legal right to have a direct payment. However the Guidance makes it clear that CCGs ought to provide a personal health budget (via one of the options) to eligible patients. It states:

"If an individual comes within the scope of the 'right to have' a personal health budget, as outlined in section 4 above, then the expectation is that one will be provided.

There may be some exceptional circumstances when a CCG considers a personal health budget to be an impracticable or inappropriate way of securing NHS care for an individual. This could be due to the specialised clinical care required or because a personal health budget would not represent value for money as any additional benefits to the individual would not outweigh the extra cost to the NHS. However, evidence from the pilot and learning from CCGs that are already rolling out personal health budgets in these areas suggests that there will be few cases where a personal health budget cannot be provided"

14.4 However many patients in residential care are eligible for NHS Continuing Healthcare. The Guidance makes it clear that a personal health budget would not be appropriate for such patients. It provides:

"Can personal health budgets be provided to people in nursing/residential care home settings?"

The Government's intention is for all people receiving NHS CHC or CC to have the "right to have" a personal health budget where they would benefit.

The National Health Service (Direct Payments) Regulations 2013 and "right to have" announcement do not explicitly limit this to people living in their own homes. Individuals assessed as eligible for NHS CHC or CC funding may live in nursing or

⁹ See http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/2014/Personal_health_budgets_right_to_have_guidance.pdf

residential care and they too may benefit from receiving care via a personal health budget.

Where a request for a direct payment for healthcare is made for a person living in a residential setting the CCG must be certain that providing care in this way adds value to the person's overall care. Generally, direct payments should not be used to pay for care and support services being commissioned by the NHS that a person will continue to access in the same way whether they have a personal health budget or not. In such instances, where no additional choice or flexibility has been achieved by giving someone a personal health budget, then allocating a direct payment only adds an additional financial step and layer of bureaucracy into the commissioning of the care.

CCGs need to be clear that the use of a direct payment in such settings is cost effective and is a sensible way to provide care to meet or improve the individual's agreed outcomes.

The use of direct payments for adults within residential settings was not tested as part of the personal health budget pilot and the benefits of providing care in this way are not known. There is a pilot programme underway in residential settings considering the use of direct payments for personal budgets in social care and the Department of Health will use the learning and evidence from this programme to inform guidance. This will then be used to support the introduction of direct payments for people receiving social care and living in residential care from April 2016.

Learning from the residential care pilot will help inform national policy developments in the NHS around the use of direct payments in residential settings. In the meantime, although there is no prohibition on using direct payments for those in residential care, CCGs should be cautious about offering a personal health budget in this form.

Other types of personal health budget, for example notional budgets, can be used where direct payments are not a practical route and many people may find great benefit in planning their care using the personalised care planning process associated with developing a personal health budget"

- 14.5 No steps have yet been taken to introduce direct payments for people receiving social care and living in residential care. It is unclear if this is still government policy or whether further Regulations will be made in the future to carry forward this policy.
- 14.6 Where a health body does agree to provide a personal health budget, there are 3 way in which a personal health budget can be delivered. The 3 options are identified at Regulation 32A(2) namely:
- a) A direct payment arrangement in accordance with the 2013 Regulations. If this is set up for an NHS Continuing Care Healthcare patient or for representative where a child is in

receipt of Children and Young People's Continuing Care, it will operate in the same way as any other direct payment arrangement;

- b) A "notional" personal health budget set the health body in accordance with the outcome of discussions with the eligible person or that person's representative as to how best to secure the provision of the relevant health service to the person. This is described at paragraph 3.2 of the Guidance as:

"A notional budget - where the commissioner (for example the CCG) holds the budget but utilises it to secure services bases on the outcome of discussions with the service user"

- c) The third option is to make a direct payment to a person who applies the money in accordance with the outcome of discussions with the eligible person or that person's representative as to how best, with the agreement of the relevant body, to secure the provision of the relevant health service to the eligible person. This is described as follows at paragraph 32 of the Guidance:

"A third party budget - where an organisation independent of the individual and the NHS manages the budget on the individual's behalf and arranges support by purchasing services in line with the agreed care plan"

- 14.7 The 2012 Regulations do not define the types of services that are required to be included in a "personal health budget". However, the Guidance suggests that these should be the same services that could be part of a direct payment arrangement (and should not include services that are excluded from a direct payment arrangement. The Guidance states at paragraph 5 (page 12):

"Personal health budgets are not appropriate for all types of healthcare. There are particular exclusions for their use where the personal health budget is received as a direct payment and a full list can be found in the National Health Service (Direct Payments) Regulations 201327. Although the regulations refer specifically to direct payments, for consistency and good practice the exclusions should be applied to all types of personal health budgets"

- 14.8 The Guidance suggests that the third option should be limited to circumstances where an independent third party organisation acts as a commissioner of healthcare for the patient, in accordance with the outcome of discussions with the patient or the patient's representative

as to how best, with the agreement of the health body, to secure the provision of the relevant health service to the eligible person. The need for the health body to “agree” the provision means that the health body has the final say as to how NHS money should be used. It is thus difficult to see that this option adds anything substantial to the direct payment arrangements. The governance arrangements under this option are also not spelled out in the 2012 Regulations.

14.9 The changes to the 2012 Regulations appear to have been driven by a desire by the government to increase the take up in direct payment arrangements for patients who are eligible for NHS Continuing Healthcare or Continuing Care for Children. However badging this as a case where a patient has a “right” to a personal health budget is misleading the 2012 Regulations do not create a right for a patient to have a personal health budget. However the 2012 Regulations may have caused a change in practice by emphasising the normality of direct payment arrangements for patients with long term conditions.

15 Legal issues that can arise with direct payments

15.1 There are several legal issues that can arise as part of care planning under direct payment arrangements. The following particular legal issues can arise:

- a) The employment of family members;
- b) Top Ups, wealthy patients and patients with substantial damages payments; and
- c) Whether to support a direct payment to for a home care package or commission a care home placement.

15.2 **The employment and payment of family members as part of the care plan:** Section 3(1) of the Children Act 1989 defines the term “parental responsibility” as meaning “all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property”. However, a general parental duty to “look after” a child cannot amount to a legal duty to provide 24-hour, 7 day a week specialist medical care to a disabled child. Many parents of disabled children become “expert carers”. Their exposure to the child’s medical condition over an extended period, their own interaction with doctors,

nurses and care staff and seeing the first-hand effects of different treatment regimes means parents (or those standing in the place of parents such as foster carers) can become as knowledgeable about their child's condition as any formally qualified medical professional. This can both be a source of high quality care but also, on rare occasions, a serious risk to the health of the child, particularly if parents provide treatment for their child which deviates significantly from established clinical practice.

- 15.3 If parents are delivering far more care than they could be called upon to provide as part of their parental responsibilities, there is no reason in principle why the NHS should not permit a direct payment to be used to pay a parent for delivering these services. Parents of disabled children often give up jobs or forgo career advancement in order to free up time to provide round the clock care to a disabled child. If the parent did not provide these services, a non-family carer would have to be employed to provide care to a child in place of a family member. However where the family member knows the child far better, it is often possible for the family member to deliver excellent care in place of external carers. Further, keeping the family finances afloat is plainly in the child's best interests and can be in the NHS's interests, particularly if payment to the parents keeps the household viable and thus avoids the need for an expensive care home package.
- 15.4 The position with adults is more straightforward. Family members may have a moral duty to support adults in their family but there is no legal duty to do so. Prior to the National Assistance Act 1948, the Poor Law schemes placed a legal duty on families to provide care and support to a wide range of relatives. The only people who ended up in the workhouse were those who had no relatives who could be prevailed upon to support them. However, that all changed in 1948 when the legal duty to support family members was abolished. Despite the absence of a legal duty, many disabled adults receive care and support from their family members, including parents of disabled adults and those caring for a disabled parent. The observations above about parents looking after disabled children apply equally to the care of adults by family members. At its best, it can be superb levels of care and, at its worst, it can be inadequate care where the control of the property prevents the NHS being able to deliver on its duties to the patient. The "best" case scenario is far, far more common than the worst case scenario.

15.5 However, the paid employment of family members to provide care to an NHS patient gives rise to some difficult issues and tricky conflicts of interest which need to be managed carefully. A paid member of the family becomes someone who is paid by public funds to deliver a care service and is thus accountable for the services that the carer provides. He or she can be required to follow care protocols and make proper notes when that may not be the case where care is unpaid. On 14 October 2013 the 2013 Regulations were amended by the National Health Service (Direct Payments) (Amendment) Regulations 2013 to provide specific provisions concerning the employment of family members. These Regulations inserted a new Regulation 8(5A) which provides:

“A health body may specify in a care plan that a service may be secured in respect of a patient from a person who is an individual living in the same household as the patient, a family member mentioned in regulation 7(8), or a friend involved in the provision of the patient's care, whether or not a nominee, only if a health body is satisfied that to secure a service from that person is necessary—

- (a) to meet satisfactorily the patient's need for that service; or
- (b) to promote the welfare of a patient who is a child”

15.6 Thus a person “in the same household as the patient” can only be employed to provide services to the patient if the test in (a) or (b) is met. In this context, the word “necessary” probably does not mean “essential so no other option is possible” but “appropriate and proportionate” in all the circumstances of the case. The Guidance says as follows about the employment of family members (although this says little more than reproduce the wording of the Regulations):

“153) A direct payment can only be used to pay an individual living in the same household, a close family member (see Box 3 for a definition of a ‘close family member’¹⁰) or a friend if the CCG is satisfied that to secure a service from that person is necessary in order to satisfactorily meet the person receiving care’s need for that service; or to promote the welfare of a child for whom direct payments are being made. CCGs will need to make these judgements on a case by case basis.

154) These restrictions are not intended to prevent people from using their direct payments to employ a live-in personal assistant, provided that person is not someone who would usually be excluded by the regulations. The restriction applies where the relationship between the two people is primarily personal rather than contractual, for example if the people concerned would be living together in any case”

¹⁰ Box refers to the list of close family members in Regulation 7(8) which is set out at paragraph 7.1 above.

- 15.7 The test introduced by the amended Regulations is, in practice, pretty meaningless. A care co-ordinator could almost always conclude that it is necessary for an appropriate family member to be employed to provide support to a patient. Equally, if the care co-ordinator concluded that it was inappropriate family member to be employed to provide support to a patient, care for the patient from that person should not be included in the care plan. If a proposal is made to pay a family member to provide care the health body may wish to pay particular attention to this proposal as part of its consultations.
- 15.8 There are a series of governance issues which arise where family members are providing paid care to a patient as part of NHS funded care including:
- a) **Should there be separation of the “representative” and the paid carer:** There is nothing in the 2013 Regulations which prevents the representative also being paid to provide care to the patient. The representative could not be “employed” because he or she would be both the employer and the employee. He or she would thus have to be a self-employed carer and would be responsible for their own income tax and national insurance payments. The direct payment should also allow funds to enable the representative to make pension arrangements in the same way as if the representative were an employee. In order to ensure conflicts of interest are properly managed, the care plan should set out clearly that the representative will be employed and should detail the level of payment to be made to the representative;
 - b) **The need for proper contracts of employment:** Family members (other than any representative) should be provided with proper contracts of employment by the patient or the representative. The contract should set out the responsibilities on both sides;
 - c) **Adherence to professionally agreed care plans:** Family members who are paid to provide care to a vulnerable patient should be asked to confirm that they will provide care in accordance with the care plan and will follow any protocols set up by professional medical staff for the patient. Where a home-care package is working well, professionals and family members will pool their knowledge and skills to devise care plans. However once protocols are agreed, the health body needs to know that family members will provide appropriate care, and that normally means agreeing to provide care in accordance with protocols devised under the care plan;

- d) **Suitable amounts of time off and holidays:** The health body should be cautious to ensure that a family member does not agree to take on an excessive workload and that proper arrangements are put in place to allow time off for the family member, with funded respite care if needed. It has to be in the interests of all parties that any direct payment is a long-term, sustainable arrangement, and this will require a key family member having time away from delivering care;
- e) **Record keeping:** Professional care staff keep records of the care provided to a patient. If family members are paid by the NHS to provide care, the health body needs to reach agreement with the family member about how records will be made about the number of hours that a family member provides care and the material events that occur during any period when care is provided;
- f) **Insurance:** Care staff should be insured for the mutual benefit of themselves and the patient. Family members who provide care should be in the same position, with appropriate insurance funded by the direct payment; and
- g) **Reviews and the suitability of a home care placement:** The existence of an income for family members from a direct payment will inevitably mean that the family finances will become dependent on the continuance of this source of revenue. If a patient has a progressive condition, there may come a time when a care home placement is more clinically appropriate but some family members may be understandably reluctant to agree to this because, in part, it will lead to cessation of the direct payment income. Health bodies should be mindful of this potential conflict of interest when conducting reviews.

15.9 None of these issues should prevent a care plan providing for paid care to be provided by family members in a suitable case. However the health body needs to be acutely aware of the potential conflicts of interest that arise where a family member's personal financial interests are involved.

Top Ups, wealthy patients and patients with substantial damages payments:

15.10 Arrangements under which service users pay part of the fees for a care home which provides an enhanced service above the base level that the state is prepared to fund are common in social care. However, they are generally prohibited when a patient is getting NHS funded care. The NHS Choices website explains¹¹:

“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”

15.11 Thus wealthy patients are generally left with a choice between a care home placement at a level that the NHS is prepared to fund or accepting the whole cost of funding a higher quality placement for themselves. This can be a source of tension between patients, families and NHS commissioners, particularly where a patient has received a damages payout which is supposed to include the cost of funded care.

15.12 The law around personal injury (and in particular clinical negligence) payments provides that a claimant has the right to claim privately funded health services as part of a damages claim: see section 2(4) of the Law Reform (Personal Injuries) Act 1948. Provided a claimant genuinely has an intention to seek privately funded medical treatment at the time the damages award is made, the court cannot look into the reasonableness or otherwise of the decision to seek private medical care as opposed to accessing NHS services: see *Eagle v Chambers (No 2)* [2004] 1 WLR 3081 at §69 to §72.

15.13 However once a settlement of a personal injury claim has been agreed, particularly if the settlement is by way of a lump sum payment, the claimant is fully entitled to “change his or her mind” and claim NHS services. At that point, the patient is entitled to be treated in the same way as any other patient. Hence, a patient who has been the subject of a clinical negligence award based on negligent NHS treatment and which claimed compensation based

¹¹ See <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx>

on privately funded care is nonetheless is entitled to seek NHS funded care (which will be free at the point of use). An NHS commissioner cannot conclude that a patient does not have a “reasonable requirement” for healthcare services because of a damages award in favour of the patient: see *R (Booker) v NHS Oldham & Anor* [2010] EWHC 2593 (Admin). However a patient who is wealthy is only entitled to the same level of NHS services as a patient who is destitute. The “needs” of the patient are not adjusted to reflect the lifestyle of the patient prior to the provision of NHS services. This can often lead to difficulties and to requests by a patient to “upgrade” services funded by the NHS.

15.14 Outside of direct payments, there are continuing difficulties around the extent to which direct payments may be used to sidestep restrictions which the NHS commissioner seeks to put on the level or cost of care for a patient or to support a home care package when care could be commissioned in a care home at a cheaper rate. It is often considerably more expensive for individuals with long term conditions to be provided with a comprehensive package of specialist care in their own homes as opposed to being provided with care in a care home environment where economies of scale can, to some extent, reduce the cost for each individual patient. CCGs and NHS England have a duty under section 3(1) NHS Act to provide services to meet the reasonable requirements of relevant patients for a range of health and social care services. Arranging to have these services delivered to the patient way of a direct payment is one method by which the CCG or NHS England can discharge the duty under section 3(1) (and indeed is a method by which the CCG or NHS England could discharge any other duty to the patient as long as the services are not exempt under the Regulations. However, the fact that payments to support a care plan is being sought by way of direct payments does not impose any legal duty on the CCG or NHS England to expend more money on supporting an individual patient than is required to discharge the primary duty. CCGs are often confronted with the problem that continuing a bespoke arrangement under which a package of services is provided at a person’s own home is more expensive than funding a care home placement. This can arise whether the care is funded by a direct payment or in the traditional way.

15.15 This issue was considered by the High Court in *Gunter v South Western Staffordshire Primary Care Trust* [2005] EWHC 1894 (Admin)¹². This case arose prior to direct payments but the family attempted to persuade the NHS commissioner to set up a “User Independent Trust”

¹² See <http://www.bailii.org/ew/cases/EWHC/Admin/2005/1894.html>

("UIT"), which was an attempt by Rachel Gunter's family to get around the then bar on direct payments by setting up a contract between the UIT. The UIT would then use the money provided by the PCT to employ the staff needed to provide care to Rachel Gunter at home, supplemented by care provided by family members. The PCT was concerned whether there was power to set up a contract and agreed that it may be a sensible way to avoid the care agency's profit, which was estimated at add 35% to the overall cost. The UIT was thus seen by the family as making a home care package more affordable. Mr Justice Collins confirmed that the PCT had power to explore this option and would need to justify any decision that moved her from her home when this was not her preferred option. The Judge said at §20:

"It is apparent that to remove Rachel from her home will interfere with her right to respect for her family life. Mr Wise has also relied on the positive need to give an enhanced degree of protection to the seriously disabled. This is in my view an unnecessary refinement. The interference with family life is obvious and so must be justified as proportionate. Cost is a factor which can properly be taken into account. But the evidence of the improvement in Rachel's condition, the obvious quality of life within her family environment and her expressed views that she does not want to move are all important factors which suggest that to remove her from her home will require clear justification"

15.16 However, bearing in mind cost was a factor, the Judge also added the following cautionary words at §28:

"The claimant and her parents cannot assume that home care will necessarily result. I certainly hope that it can since it is obviously benefiting Rachel. But 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. The risks to Rachel must also be carefully assessed"

Thus, the case supported the general framework but let the parties sort out the details.

15.17 The next relevant case was *R (S) v Dudley PCT* [2009] EWHC 1780 (Admin). This was an application for permission to apply for judicial review by the patient who challenged the failure of the PCT to pay the entire cost of care for Mr S who was discharged to Prestwood House near Stourbridge after a stay in hospital. The case has limited weight because permission was refused, albeit after a full judgment by Mr Justice Mitting. However it shows the level of discretion available to a NHS commissioner and is thus of some use.

15.18 Mr S was eligible for NHS continuing healthcare and thus this was NHS funded care rather than social care. The Judge explained that:

“There are two buildings within the grounds of Prestwood House; the house itself and the Coach House. Different rates of charge are made by the operators of the house for residents in two buildings. The claimant was discharged to the Coach House at, it seems, his own and his family's request”

15.19 The PCT was prepared to fund Mr S in the main house at their standard rate, but his family insisted that he should be accommodated in the Coach House. Thus the PCT entered into a contract with the care home for the standard rate and the family “topped up” the care by a separate contract. Mr S then challenged this arrangement on various grounds saying it was an unlawful top up. The Judge noted at §21 that the PCT’s position was as follows:

“The defendant had a standard rate which it was willing to pay for continuing health care of £471 per week. She noted that 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”

15.20 The PCT justified its position by reference to various provisions allowing NHS patients to pay for enhanced services within hospitals. That argument was accepted by Mr Justice Mitting who rejected the patient’s challenge. Thus, on the particular facts of this case, the NHS had acted lawfully in part-funding the cost of the care home. However, the arrangement would have been unlawful if the care home had not offered to fund a placement at the standard rate.

15.21 That raises the question as to whether a “direct payment” arrangement could be used to circumvent the general prohibition on co-funding NHS services. This is not a subject which is covered in the Guidance but, as a matter of principle, there could be no legitimate objection to a patient or representative committing to using their own funds to meet a certain part of the care needs from their own resources. If that commitment were to be given, the health

body would not be obliged to provide services to meet that “need” because it would be met from the patient’s own resources. There is a possible analogy here with an NHS Continuing Healthcare patient who has their own home (funded from their own resources) and thus does not have a “need” for accommodation funded by the NHS. Thus if, by way of example, the patient has a need for a single overnight carer, but commits to funding that need from a damages claim, the health body can legitimately exclude that “need” when calculating the level of a direct payment. That may make the continuance of a home care package affordable for a health body whereas, without that element of care being funded by the health body, a care home place may be significantly cheaper and so a home care package may not be offered.

- 15.22 The same logic could be used to fund a care home placement if the care home was prepared to divide the cost into services that the patient agreed to fund and those that the health body agreed to fund. Regulation 13(1) provides that the health body must be satisfied that the direct payment meets the “full cost of the services specified in the care plan”. However if a care home’s basic charges were £X per week but the patient required additional services costing £Y per week, there is probably no reason why the patient should not commit to meeting the cost of the additional services and thus leaving the NHS only funding the core service provision. This is an area where the lawfulness of top-up payments will depend on the way that packages of care are structured. In a time of tight constraints, it seems unlikely that the NHS will be able to hold to the principle that there should be no co-funding of care home packages,

Whether to support a direct payment to for a home care package or commission a care home placement

- 15.23 Commissioning care for patients with complex needs in their own homes is often the ideal. However creating all the facilities to enable a patient to have a bespoke “hospital at home” can be prohibitively expensive. NHS commissioners thus frequently have to face the difficult question as to whether to discharge their duties to the patient by offering to commission a care home placement or whether to continue to meet the escalating costs of a home care package. Patients who seek a direct payment do not avoid the resource constraints involved in any NHS commissioning decision. Accordingly the question as to whether the a home care

package provides value for money for the NHS arises in the context of a direct payment arrangement in the same way as it does with directly commissioned packages of care.

15.24 Health bodies have a duty to “respect” the home of a patient as a result of their duties under article 8 ECHR. However it is questionable whether that duty extends to a requirement to spend more resources on the patient in order to keep them in their own home where there is intense competition for resources between patients: see the discussions of the interplay of ECHR rights and resources in *R (Condliff) v North Staffordshire Primary Care Trust* [2011] EWHC 872 (Admin)¹³.

15.25 Some CCGs have adopted policies which operate a “buffer” under which a home care package will continue to be funded as long as the cost is not more than a fixed percentage (say 10%) more than the cost of an appropriate care home package. The lawfulness of such a policy has never been challenged but it is hard to see any basis on which such an approach could be alleged to be unlawful.

¹³ See <http://www.bailii.org/ew/cases/EWHC/Admin/2011/872.html>