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**PRIORITY ALTERED STATE OF CONSCIOUSNESS**

[**ASC Every Day**](#_top)

* Statements made by medical experts in support of NHS Continuing Care package.

**PRIORITY ALTERED STATE OF CONSCIOUSNESS**

[**Does Not Respond to Medication**](#_top)

* Statements made by medical experts in support of NHS Continuing Care package.

**PRIORITY ALTERED STATE OF CONSCIOUSNESS**

[**Severe Risk of Harm**](#_top)

* Statements made by medical experts in support of NHS Continuing Care package.

**PRIORITY ALTERED STATE OF CONSCIOUSNESS**

[**Characteristics of Need**](#_top)

* Statements made by medical experts in support of NHS Continuing Care package.
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* Statements made by medical experts in support of NHS Continuing Care package.

**PRIORITY ALTERED STATE OF CONSCIOUSNESS**

[**Statement by Medical Experts on Primary Health Need**](#_top)

* Statements made by medical experts in support of NHS Continuing Care package.

**IDENTIFIED PRIMARY HEALTH NEED**

[**November 2017 Review**](#_top)

* Statements made confirming identification of primary health need in November 2017 Review.

**IDENTIFIED PRIMARY HEALTH NEED**

[**January 2018 Review**](#_top)

* Statements made confirming identification of primary health need in January 2018 Review.

**IDENTIFIED PRIMARY HEALTH NEED**

[**Head of CHC at West Hampshire CCG**](#_top)

* Statements made confirming identification of primary health need in February 2018 Local Resolution Meeting.

**IDENTIFIED PRIMARY HEALTH NEED**

[**Medical Experts**](#_top)

* Statements made by medical experts in support of NHS Continuing Care package.
* Statements made by medical experts in support of NHS Continuing Care package.

**PROCESS FAILURES**

[**Billing Issue with Agency**](#_top)

* Agency informed \_\_\_ that they could only provide \_\_ hours per week due to the CCG.
* CCG stated that they did not have information on their system about the arrangement.

**PROCESS FAILURES**

[**Should Not Have Had Review**](#_top)

* CCG informed about the funding arrangement.
* Despite information provided, they stated, *“It is part of CHC funding protocol for clients to have a review every 6-12 months, this with a request for an increased package of care, has prompted our case coordinators to request me to arrange a review meeting.”*
* The first statement is misleading. The National Framework states 6-12 months, but the CCG’s Joint Operational Policy states annual reviews.
* \_\_\_ sent email the next day. Stated how package of care set up.
* We received a reply from the CCG on the same day. *“I have passed your email to \_\_\_ and the duty team to look into, as they will be best to advise on the other points you have raised.”*
* No contact received and the review took place on 8th November 2017.
* \_\_\_\_\_\_\_ (November Review meeting)
  + Statements made by Case Coordinator.
* \_\_\_\_\_\_\_ (January Review meeting)
  + Statements made by Case Coordinator.

**PROCESS FAILURES**

[**Process in November 2017 Review**](#_top)

* Process failures included:
  + Failure to read supporting statements from \_\_\_ RGN and \_\_\_.
  + Refused to discuss comparisons with previous DSTs and Reviews.
  + Accused \_\_\_ and \_\_\_ of being unprofessional for asking for previous documents to be discussed.
  + \_\_\_\_\_\_\_ (Case Coordinator) had not prepared appropriately for the meeting, including failing to read important information regarding the case.
  + Trying to continue the meeting during the temporary absence of \_\_\_, in contravention to emailed request.
  + Impact on well-being not appropriately considered.
  + Reasoning for reduction in hours based on inexcusable misrepresentation of clinical records.
  + Changing of opinion from PHN to MDT after informed appeal would be launched if reduction of hours was recommended.
  + Carers assessment was not discussed, despite assurances prior to the meeting.
  + Refusal to discuss previous reviews, preventing opportunity to highlight amendments required to April 2017 review, as offered in prior email.
* Email was sent to CCG on 10/11/17 to request that additional information (regarding process of the review) be considered by panel before accepting recommendation.
* Informed by CCG that panel are not involved at this stage. Recommendation will stand.
* Formal complaint submitted on 10/11/17 regarding the process of the review.

**PROCESS FAILURES**

[**Outcome of November 2017**](#_top)

* Report received, after numerous requests, on 8/12/17.
* The report contained false, inaccurate, misleading, misrepresentations and omissions. These have rendered the report inaccurate.
* \_\_\_ reported this to the CCG on 10/12/17.
* No response received from the CCG.
* Formal complaint response contained no reference to errors within the report.

**PROCESS FAILURES**

[**MDT Cancellation**](#_top)

* Sequence of events/emails that eventually led to cancellation of MDT from November 2017 Review.

**PROCESS FAILURES**

[**November Formal Complaint**](#_top)

* Areas addressed were upheld.
* Unsatisfactory or no response to:
  + Carers assessment,
  + Accusation of being unprofessional,
  + Trying to continue meeting during the temporary absence of \_\_\_,
  + Changing of opinion,
  + Amendments to April 2017 review,
  + Our desired outcomes were not referenced in the response. The report is still on file, despite a request to have it made void. No explanation given. No reassurance provided that \_\_\_ would be held to account.
* Request for new review upheld.
  + Outcome did not meet CCG’s complaints policy – *“The underlying approach promoted by the Principles for Remedy is for the service provider to restore the complainant to the position they would have been in if the maladministration or poor service had not occurred.”*
  + Outcome should have upheld the original decision recognising the Primary Health Need.

**PROCESS FAILURES**

[**Report from November 2017 Review – False, Misleading, Misrepresentation and Omissions**](#_top)

* The report was received on 8/12/17, following five requests for it.
* The report contains information that is:
  + False.
  + Factually inaccurate.
  + Misleading.
  + Misrepresenting clinical information.
* The report omits significant information.
* We stated, on 5/12/17, that our response to the report needs to be considered before the complaint is resolved.
* Concerns were raised with CCG on 10/12/17, two days after receipt of the report.
* The CCG made no contact to ascertain our concerns.
* Report analysis and evidence provided to CCG during January 2018 Review and meeting with \_\_\_ and \_\_\_ on 15/2/18.
* November report referenced in January Review report.

**PROCESS FAILURES**

[**Carers Assessment**](#_top)

* Sequence of events that demonstrate failure to organise a carer’s assessment despite multiple requests.

**PROCESS FAILURES**

[**Outcome of January 2018 Review**](#_top)

* *Statements that prove the conversation that took place demonstrating primary health need but recommendation for MDT.*

**PROCESS FAILURES**

[**Process of January 2018 Review**](#_top)

* CHC Clinical Review Form Completed.
* Gradings made against all DST domains.
* Family not informed before the review that this would be required.

**PROCESS FAILURES**

[**Three Reviews in Nine Months All Done Differently**](#_top)

* April 2017 Review
  + Supporting statements provided to Case Coordinator.
  + Case Coordinator satisfied that the evidence in the letters demonstrated that there would be no change to eligibility.
  + Form completed – ‘light touch’ approach.
  + Previous reviews and DST not present at the meeting.
  + Package maintained.
* 8th November 2017 Review
  + Some supporting statements ignored.
  + Refusal to discuss previous reviews and DST.
  + Case coordinator wanted to make an *“independent”* judgement.
  + Primary Health Need accepted but wanted to negotiate package.
  + Changed view to, *“I think there might not be a Primary Health Need.”*
  + MDT Recommended.
* 24th January 2018 Review
  + Supporting statements accepted.
  + References made to previous reviews and DST.
  + DST summary available at the meeting only.
  + MDT recommended due to *“minor changes”*.
  + Under challenge about the recommendation, Case Coordinator stated that it is *“simply the guidelines”*.
  + Case coordinator confirmed with \_\_\_ (Senior Manager, Band 8). MDT has to be recommended due to minor changes. This was confirmed with \_\_\_ within 75 minutes of the end of the meeting.

**PROCESS FAILURES**

[**Amendments to January 2018 Review Report**](#_top)

* Emails and conversations regarding issues relating to post-review amendments within the report.

**PROCESS FAILURES**

[**Procedure for February 2018 Formal Complaint**](#_top)

* Evidence of issues regarding formal complaint process.
* Evidence of issues regarding formal complaint process.

**PROCESS FAILURES**

[**Procedure for Confidential Letter to \_\_\_ (Chief Officer)**](#_top)

* Following serious concerns about process for the CHC review and the complaints process, a letter, marked as confidential, was sent via email to \_\_\_ on 15/2/18.
* The letter stated the concerns regarding the two processes and asked if \_\_\_ would like to investigate the matter personally or if she would like us to refer the matter to the Parliamentary and Health Service Ombudsman.
* The email was sent to WHCCG.info@, rather than the Patient Experience and Complaints Service email address of WHCCG.yourfeedback@.
* \_\_\_, PECS Manager for both of our formal complaints, sent a letter on 16/2/18 stating, *“I also acknowledge receipt of your emailed letter of 15 February 2018 addressed to* \_\_\_*, which will be addressed in* \_\_\_*’s response. As previously advised you should receive a full response by 14 March 2018.”* This response was also sent to \_\_\_ MP.
* If they are following their complaints policy, this means that \_\_\_ will be the PECS manager for a complaint against her and will draft and redraft the response.
* The indication that \_\_\_ will respond in misleading. The complaints policy clearly states that the Chief Officer only gives final approval and signature.
* The single question in the letter has not been responded to and cannot be part of the response for 14 March 2018 as the matters are different.

**MISINFORMATION**

[**WHCCG Employee 1**](#_top)

* Misleading statements by WHCCG Employee 1

**MISINFORMATION**

[**WHCCG Employee 2**](#_top)

* Misleading statements by WHCCG Employee 2

**MISINFORMATION**

[**WHCCG Employee 3**](#_top)

* Misleading statements by WHCCG Employee 3

**MISINFORMATION**

[**WHCCG Employee 4**](#_top)

* Misleading statements by WHCCG Employee 4

**MISINFORMATION**

**[WHCCG Employee 5](#_top)**

* Misleading statements by WHCCG Employee 5
* Misleading statements by WHCCG Employee 5

**THE LAW AND OMBUDSMAN**

[**Care Act 2014**](#_top)

* 92 Offence – False or misleading information
  + A Care provider of a specified description commits an offence if-
    - it supplies, publishes or otherwise makes available information of a specified description,
    - the supply, publication or making available by other means of information of that description is required under an enactment or other legal obligation, and
    - the information is false or misleading in a material respect.

**THE LAW AND OMBUDSMAN**

[**Care Act 2014 Statutory Guidance**](#_top)

* + 13.9 As many of the same principles apply to both care and support planning and reviews, this chapter should be read in conjunction with chapter 10 on care and support planning.
  + 13.17 In all instances, the method of review should, wherever reasonably possible, be agreed with the person and must involve the adult to whom the plan relates, any carer the adult has and any person the adult asks the authority to involve.
  + 10.2 The person must be genuinely involved and influential throughout the planning process, and should be given every opportunity to take joint ownership of the development of the plan with the local authority if they wish, and the local authority agrees. There should be a default assumption that the person, with support if necessary, will play a strong pro-active role in planning if they choose to. Indeed, it should be made clear that the plan ‘belongs’ to the person it is intended for, with the local authority role being to ensure the production and sign-off of the plan to ensure that it is appropriate to meet the identified needs.
  + 10.32 The guiding principle therefore is that the person be actively involved and is given every opportunity to influence the planning and subsequent content of the plan in conjunction with the local authority, with support if needed.
  + 10.45 In all cases, additional content to the plan must be agreed with the adult and any other person that the adult requests and should be guided by the person the plan is intended for.

**THE LAW AND OMBUDSMAN**

[**R (Clarke) v Sutton LBC (2015) EQHC 1081**](#_top)

**His Honour Judge Sycamore (Sitting as a Judge of the High Court)**

* + The claimant, who is 27 years of age, suffers from severe epilepsy.
    - 13-34 tonic-clonic seizures per year.
    - Occasional use of Buccal Midazolam.
  + The council decided to reduce the support in spite of expert evidence that the person’s condition had not improved and that reduced package would not meet his needs.
  + The court held the decision to be unlawful. The council had *“relied excessively on the non-expert view of a social worker in a face of a wealth of evidence to the contrary from appropriately qualified and experienced experts (para 28)”.*
  + *“Professionals should fully involve the person seeking support by listening to their views about how they want to live their lives and the type of care and support that best suits them and by helping them to make informed choices. This includes identifying the support the person needs to make a valued contribution to their community.”*
  + *“Although it had available to it the opinions expressed by the claimant’s consultant, GP, epilepsy nurse and care provider it effectively relied on the judgement of a social worker.”*
  + *This was in the face of evidence that the claimant’s seizures are unpredictable and that it cannot be pre-determined on which nights they will occur. According to the consultant the claimant is at risk of sudden death if there is not appropriate monitoring.”*
  + *“At the hearing before me counsel for the defendant sought to explain, in the absence of any evidence, that the basis for that provision related to the payment to be made to a member of staff who would otherwise be asleep but was actually awoken to attend to the claimant when he was having a sleep related seizure. As was observed on behalf of the claimant that formula, on the basis of the evidence available, would provide insufficient time for provision of the necessary medication in circumstances in which the claimant himself is unable to activate the alarm when unconscious.”*
  + “The defendant accepted that in the circumstances of this case, article 8 is engaged.”
  + *“It is important to keep in mind that this is a case in which the claimant has been in receipt of these services for a number of years in circumstances in which his medical team and care providers have made it clear that his needs have not decreased.”*
  + *“I am satisfied that the defendant’s decision that the claimant should be expected to move from his home… does amount to an unlawful interference with the claimant’s rights to respect for home and private life.”*
  + *“On the basis of the assessment, which I have deemed to be inadequate…”*
    - h

**THE LAW AND OMBUDSMAN**

[**R v North and East Devon Health Authority, ex parte Coughlan (2000)**](#_top)

* Local Authorities can only legally provide healthcare services that were:
  + Merely incidental and ancillary to the provision of accommodation which a local authority is already under duty to provide.
  + Of a nature, which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide.
* Ultimately the Coughlan case highlighted that if an individual has healthcare needs that are over and above that which social services can be expected to provide and are therefore primarily health needs, the NHS has a responsibility to provide for those needs, and to fund the necessary care.

**THE LAW AND OMBUDSMAN**

[**R (Whapples) v Birmingham Crosscity CCG (2015)**](#_top)

* The Court approved 2012 guidance that in such cases NHS bodies were *“financially responsible for all health and personal care services and associated social care services to support assessed health and social care needs and identified outcomes for that person, e.g. equipment provision (see PG 79), routine and incontinence laundry, daily domestic tasks such as food preparation, shopping, washing up, bed - making, support to access community facilities, etc. (including additional support needs for the individual whilst the carer has a break)”.*
  + - j

**THE LAW AND OMBUDSMAN**

[**Brighton & Hove City Council (15 017 591)**](#_top)

* + *“A decision in direct contravention of the care manager’s recommendations by a panel who was not involved in the assessment. I found the Council was at fault in the way it dealt with this ‘funding application’.”*

**THE LAW AND OMBUDSMAN**

[**Norfolk (15 016 495)**](#_top)

* + *“The Council has not been able to explain why it believed Ms B’s needs had reduced and in what areas when she provided evidence of her medical conditions and set out how they were causing her health to deteriorate and her needs to increase.”*

**THE LAW AND OMBUDSMAN**

[**Bromley (15 020 384)**](#_top)

* + *“An assessment must seek to establish the total extent of needs [Guidance 6.10], regardless of any support being provided by a carer [6.15].”*
  + *“Information on the care the carer is providing can be captured during assessment, but it must not influence the eligibility determination [6.15].”*
  + *“The Care Act Guidance says assessments and reviews must be carried out by assessors with the necessary expertise (using expert advisors if required). In the majority of cases assessors should therefore be capable of applying their own professional judgment from their personal knowledge of the family to make the necessary decisions.”*

**THE LAW AND OMBUDSMAN**

[**Montgomery v Lanarkshire Health Board [2015] UKSC 11**](#_top)

* The doctor is under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in proposed treatment, and of reasonable alternatives.
* A risk is ‘material’ if a reasonable person in the patient’s position would be likely to attach significance to it, or if the doctor is or should be reasonably be aware that their patient would be likely to attach significance to it.

**CONTINUING HEALTHCARE**

[**NHS CHC National Framework**](#_top)

* + 33. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual’s assessed health and social care needs.
  + 35. Unpredictability: This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the person’s health if adequate and timely care is not provided.
  + 42. The process of assessment and decision-making should be person-centred.
  + 43. Access to assessment, decision-making and provision should be fair and consistent.
  + 44. Assessments of eligibility for NHS continuing healthcare and NHS – funded nursing care should be organised so that the individual being assessed and their representative understand the process, and receive advice and information that will maximise their ability to participate in informed decision-making about their future care. Decisions and rationales that relate to eligibility should be transparent from the outset for individuals, carers, family and staff alike.
  + 56. The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on NHS continuing healthcare eligibility.
  + 60. The individual and their representative should be enabled to play a central role in the assessment process. It is important that those contributing to the comprehensive assessment have the relevant skills and knowledge.
  + 80. They [the individual] should be given every opportunity to participate in the assessment. The assessment process should draw on those who have direct knowledge of the individual and their needs. It should also make use of existing specialist assessments.
  + 81. The evidence and the decision-making process should be accurately and fully recorded.
  + 92. The CCG should not refer a case back, or decide not to accept a recommendation, simply because the multidisciplinary team has made a recommendation that differs from the one that those involved in making the final decision would have made, based upon the same evidence.
  + 139. Reviews should then take place annually, as a minimum. It is expected that any previously completed DST will normally be available at the review and each of the domains and previously assessed need levels considered by the reviewer. This should be done in consultation with the person being reviewed and any other relevant people who know the person who are present at the review. However, the focus of the review should not just be on whether the individual remains eligible for NHS continuing healthcare but on whether needs are being met and whether the package of care remains appropriate.
  + 147. If they are dissatisfied with:
    - the procedure followed by the Board or a CCG in reaching its decision as to the person’s eligibility for NHS continuing healthcare, or
    - the decision regarding eligibility for NHS continuing healthcare.
  + 153. The key principles for resolving disputes… involvement of the individual or their representative as far as possible, including the opportunity for them to contribute and to comment on information at all stages.
  + 162. CCGs are responsible for:
    - ensuring consistency in the application of the national policy
    - implementing and maintaining good practice
    - ensuring that quality standards are met and sustained.
  + PG4.3. There are many elements to a person-centred approach but as a minimum it is necessary to:
    - ensure that the individual and/or their representative concerned is fully and directly involved in the assessment and the decision-making process.
    - take full account of the individual’s own views and wishes, ensuring that their perspective is clearly the starting point of every part of the assessment process
    - obtain consent to assessment
    - keep the individual (and/or their representative) fully informed.
  + PG11.1 In applying the principle of well-managed need, consideration should be given to the fact that specialist care-providers may not routinely produce detailed recording of the extent to which a need is managed.
  + PG12.1. In considering ‘risk’ it is important to establish what particular adverse occurrence might happen and to evaluate both the likelihood and the potential impact of this occurrence.
  + PG26.2g Ensuring that the assessment and DST processes are completed in accordance with the requirements in the Framework and relevant Responsibilities Directions.
  + PG26.4. The coordinator should ensure that this takes place, including… helping the individual to understand the eligibility process as it progresses.
  + PG89. 1 When a CCG decides to support a home-based package where the involvement of a family member/friend is an integral part of the care plan then the CCG should give consideration to meeting any training needs that the carer may have to carry out this role. In particular, the CCG may need to provide additional support to care for the individual whilst the carer(s) has a break from his/her caring responsibilities and will need to assure carers of the availability of this support when required. This could take the form of the cared-for person receiving additional services in their own home.

**CONTINUING HEALTHCARE**

[**WHCCG and HCC Joint Operational Policy v4**](#_top)

* + 2.1 It provides the process for determining eligibility for NHS CHC funding and the procedures to be followed.
  + 2.3 The aim of NHS CHC is to implement the NHS CHC National Framework in order to provide appropriate care.
  + 3.5 These principles are:
    - The individual’s informed consent will be obtained before starting the process to determine eligibility for NHS CHC.
    - All individuals and their families/representatives will be provided with information to support them to participate fully in the process.
    - The process for decisions about eligibility for NHS CHC will be transparent for individuals and their families/representatives and for partner agencies.
  + WHCCG will:
    - Work in honest and open partnership with all stakeholders.
    - Be accountable for their actions both organisationally and professionally.
    - Monitor compliance against National Framework standards such as… frequency of reviews.
  + 4.4 Responsibilities
    - NHS Continuing Healthcare Team (Locality)
      * + Ensure reviews are undertaken in line with national policy.
  + 5.1 Where a person’s “primary need” is a health need, they are eligible for NHS CHC. Deciding whether this is the case involves looking at the totality of the relevant needs from the assessment process. Where an individual has a primary health need, the NHS is responsible for providing all of the health and social care to meet the individual’s needs, including accommodation, if that is part of that need.
  + 12. 1 Case reviews will be undertaken for individuals no later than three months following the eligibility decision and thereafter on an annual basis, unless a change in need or circumstance identifies an earlier review is required. This will ensure that individual is receiving the care they need and that they remain eligible for NHS CHC funding. Should a review show that following a change in need the individual may no longer meets criteria then a reassessment of eligibility must be undertaken following the DST process.

**CONTINUING HEALTHCARE**

[**Decision Support Tool for NHS Continuing Healthcare**](#_top)

* + h. The consent of the individual who is the subject of the DST must be obtained before the assessment is carried out and they should be given a full opportunity to participate in the completion of the DST.
  + 4. The individual should be given a full opportunity to participate in the assessment.
  + 5. Completion of the tool should be carried out in a manner that is compatible with wider legislation and national policies where appropriate, including the End of Life Care Strategy, long-term conditions policy, Valuing People, and the Mental Capacity Act 2005.
  + 9. The individual’s consent should be obtained before the process… and be supported to play a full role in contributing their views on their needs.
  + 13. Completion of the DST should be organised so that the person understands the process, and receives advice and information to enable them to participate in informed decisions about their future care and support. The reasons for any decisions should be transparent and clearly documented.
  + 25. It should be remembered that the DST is a record of needs and a single condition might give rise to separate needs in a number of domains. For example someone with cognitive impairment will have a weighting in the cognition domain and as a result may have associate needs in other domains, all of which should be recorded and weighted in their own right.
  + 26. Some domains include levels of need that are so great that they could reach the ‘priority’ level (which would indicate a primary health need).
  + 28. Needs should not be marginalised because they are successfully managed. Well-managed needs are still needs. There are different ways of reflecting this principle when completing the DST. For example, where psychological or similar interventions are successfully addressing behavioural issues, consideration should be given as to the present-day need if that support were withdrawn or no longer available and this should be reflected in the Behaviour domain.
  + 31. A clear recommendation of eligibility to NHS continuing healthcare would be expected in each of the following cases:
    - A level of priority needs in any one of the four domains that carry this level.
    - A total of two or more incidences of identified severe needs across all care domains.

**CONTINUING HEALTHCARE**

[**NHS Continuing Healthcare: Ensuring a Consistent Person-Centred Assessment**](#_top)

* The Process – Full consideration of eligibility for NHS CHC using the DST.
  + 5.1 Appointing a Co-ordinator.
    - Identifying suitable MDT members and securing their involvement.
    - Ensuring compliance with framework.
    - Check that consent is in place, both for undertaking the NHS CHC process and for sharing information.
  + 5.3 Assessment information required by the MDT.
    - Guidance anticipates that the MDT will usually include professionals who already have direct knowledge of the individual, and who therefore will themselves have prepared or are in the process of preparing relevant assessment reports.
  + 5.4 MDT Meeting and Completion of the DST
    - The MDT will normally hold a meeting at which the individual’s needs are discussed, the appropriate weighting on each of the DST domains is decided, and an agreed eligibility decision is reached.
    - In doing this the MDT will be drawing on the overall assessment of the individual’s needs and on any relevant records and reports from professionals involved.
    - It might be helpful for them to have some preparatory explanation regarding the nature of the MDT meeting and the fact that the DST is solely focused on needs.
    - It might also be helpful to discuss less contentious domains first.
    - The MDT is reliant on having good quality evidence-based assessments and clinical information on which to judge levels of need and the correct eligibility recommendation.
    - If the individual concerned or their representative does not agree with the domain level proposed then this should be discussed and recorded, and full account should be taken of their views.

**CONTINUING HEALTHCARE**

[**NHS England: Operating Model for NHS Continuing Healthcare**](#_top)

* CCGs are required to ensure that there is a fair and efficient process and a good quality assessment to reflect an individual’s needs.
* Provide/fund a package of care for anyone eligible for NHS Continuing Healthcare (to meet all assessed health, personal care and associated social care needs).
* Follow the National Framework.
* We need to ensure that the assessment process accurately identifies care needs.
* We need to ensure that the assessment process accurately identifies care needs… and are focused on outcomes including a positive experience of their care.
* Stakeholders said that one of the most important aspects was ensuring that the professionals with specialist knowledge of particular conditions are fully involved in the assessment process and that the implications of particular conditions or disabilities are fully understood. This is especially important where a need may rapidly change.
* Compassion is essential when supporting individuals and their families through the NHS Continuing Healthcare process.
* Good quality assessments are crucial and should be conducted professionally and with empathy whilst fully informing and involving the individual and their family. The NHS and its partners need to build and strengthen leadership for staff that work in this field, ensuring that the right staff with the right skills and training are in the right place.
* Involving the individual’s family in the process is a core component of the national framework.
* [Stakeholders] highlighted the importance of understanding the whole process from the outset and about how decisions are made.
* Most individuals being considered for NHS Continuing Healthcare will be increasingly dependent on others, which often means their families are experiencing a very difficult time.
* We must be committed to ensuring a person-centred approach to the assessment for NHS Continuing Healthcare and committed to the delivery of person-centred commissioning.
* NHS England also needs to be assured that arrangements are in place to meet the overall strategic challenges for NHS Continuing Healthcare in terms of:
  + The delivery of the National Framework as set out above.
  + Decision making that is sound and legally compliant.

**CONTINUING HEALTHCARE**

[**Improvement Framework for NHS Continuing Healthcare: Part A – “I” Statements**](#_top)

* Care
* I felt the assessment focused on me as an individual and helped me live the best life I can.
* I felt that my needs were thoroughly and accurately identified and considered within the assessment.
* I felt that the assessment process included all the relevant professionals, as well as my family, and captured all relevant information.
* I felt the assessment focused on my needs and not my financial circumstances.
* I was confident that the professionals wanted to reach the correct decision, not the cheapest or more convenient one.
* I was assessed in a way that captured the full impact of my condition and not just a snapshot on a ‘good day’.
* Compassion
  + I felt listened to and the staff tried to do everything they could to help me.
  + I felt like an individual, treated with respect and dignity.
  + I felt that all staff involved in the process showed me respect and empathy.
  + I was assessed by staff that were respectful of my feelings during the process.

* Competence
  + I believe the staff carried out my assessment professionally and effectively.
  + I believe staff had a sound knowledge and understanding of NHS Continuing Healthcare and the necessary competence to reach a fair decision.
  + I felt valued and respected by skilled staff who worked well as a team.
  + I felt listened to, my needs were understood.
  + I felt all the right information was considered.
* Courage
  + I felt staff were open and honest with me about my options and expectations.
  + I felt staff were focused on ensuring my needs, views and interests were at the centre of the assessment.
  + Staff were honest.
  + I felt confident in challenging any decisions.
* Commitment
  + I felt staff were committed to giving time to ensure my needs and views were at the heart of the process.
  + I believe staff worked hard to ensure that my assessment was carried out in the best possible way.
  + I felt I would be listened to if I raised concerns.
  + Assessments delivered within the appropriate time frame.
* Communication
  + I received clear information before, during and after each step of the process and I understand the implications.
  + I understood how decisions were made and there was a contact who could explain the decision to me.
  + I was encouraged and enabled to contribute, listened to and given the opportunity to ask questions. I had support if I needed it to make decisions for myself
  + I understand that my eligibility for NHS Continuing Healthcare is based on my assessed needs and may change if my needs change.
  + If I am found not to be eligible I am given detailed information in writing how to request a review of the eligibility decision should I choose to do so.
  + I knew where to go for information and advice.
  + I was involved in deciding when the assessment would take place and knew who would be present.
  + I felt that people understood my communication needs and tried hard to meet them.

**CONTINUING HEALTHCARE**

[**Improvement Framework for NHS Continuing Healthcare: Part B – Organisation Statements**](#_top)

* Care
  + The right people are assessed for NHS Continuing Healthcare using the national tools and they are involved in the process.
  + Arrangements are in place to provide appropriate care and support whilst people are being assessed for NHS Continuing Healthcare.
  + The assessment involved the appropriate professionals, drawing on the knowledge of others who have relevant information to contribute, and accurately identifies the person’s holistic care needs.
* Compassion
  + Assessors use the process to gain an understanding of what is important to the person and what will help to promote their independence and help them to live the best life they can.
* Competence
  + Those undertaking the role of co‐ordinator (as set out in the Framework) are trained specifically for this task.
  + Staff completing Checklists, or participating in MDTs, are appropriately trained.
  + Overall awareness of whole CHC system for all involved in CHC care pathway (e.g. hospital, community and social care).
  + Specialist knowledge and expertise is identified and made available to participate in MDTs where required.
  + Staff at all levels have the skills to work effectively in partnership across organisations to accurately identify needs and inform individual/rep as appropriate.
  + CCG governance for CHC decision‐making meets the requirements of legislation.
* Courage
  + Staff are empowered and encouraged to promote the needs and interests of individuals within the NHS Continuing Healthcare process.
  + People and systems in place to deal with individuals/families and representatives appropriately.
  + Staff are supported to raise concerns about professional standards and practice.
* Communication
  + Information is given to individuals and their representatives about the assessment process and support, information and advice is available.
  + Accurate written and verbal information about NHS Continuing Healthcare is readily made available in appropriate and accessible formats, promoted and in a range of locations.
  + The views of individuals being assessed (and/or their representatives) are recorded and considered. Systems are in place to ensure this happens.
  + Consent is sought at relevant steps in the process. Best interest processes are initiated where necessary, in accordance with the Mental Capacity Act.
  + Individual/representatives are informed in writing of the outcome of their assessment, information supporting the decision and of the eligibility decision, including the process for requesting a review of the decision.
  + Individual/representatives know who to contact.
* Commitment
  + The CCG has a person-centred approach to NHS Continuing Healthcare as set out in the National Framework.
  + CCGs adequately resource the assessment process to ensure that statutory responsibilities are met in a timely way .

**CONTINUING HEALTHCARE**

[**SFE Solicitors: Emma Boyce, Caroline Bielanska & Jennifer Margrave – Quoting National Framework**](#_top)

* + The PCT cannot refer a case back or decide not to accept a recommendation because it differs from the one they would have made based on the same evidence.
  + The individual’s needs should not be placed between levels. If it proves difficult to choose between two levels, the higher level should be selected and the reasons for the differences of opinion recorded.

**CONTINUING HEALTHCARE**

[**Response from \_\_\_ to Formal Complaint (10 November 2017) – Expectations**](#_top)

* + *“The review process… should be done in consultation with the person being reviewed and any other relevant people who know the person who are present at the review. The focus of the review should not just be on whether the individual remains eligible for NHS Continuing Healthcare but on whether needs are being met and whether the package of care remains appropriate. The outcome of the case review will determine whether the individual’s needs have changed, and that will then determine whether the package of care may have to be revised or the funding responsibilities altered.”*
  + *“With regards to the recommendation following clinical review, as discussed above, the role of the case coordinator is to highlight whether there has been a change in presentation which may lead to an increase or decrease in provision, as well as consideration as to whether a decision support tool review meeting is appropriate. The decision support tool review meeting should be facilitated when there is an indication, when aligned with the initial decision support tool, that there may be a change in outcome of NHS Continuing Healthcare eligibility.”*
  + *“The team confirm that it is expected that any previously completed decision support tool will be available at the review and each of the domains and previously assessed need levels are considered by the reviewer.”*
  + *“It is expected, in accordance with the National Framework for NHS Continuing Healthcare and also the service standard operating procedure, that reviews are inclusive of any relevant contemporaneous clinical records.”*
  + *“Whilst it is acknowledged that it is appropriate to ensure that care provision is appropriate in line with the West Hampshire Clinical Commissioning Group Choice and Equity Policy, this needs to be supported by appropriate clinical evidence in order to ensure that needs are met and safety is maintained.”*

**CONSENT AND RECORD KEEPING**

[**WHCCG: Records Management Policy**](#_top)

* 1.7 It is the responsibility of all staff including those on temporary or honorary contract, agency staff and students to comply with this policy.
* 3.1 The aims of our records management system are to ensure that:
  + Records are available when needed – from which the CCG is able to form a reconstruction of activities or events that have taken place.
  + Records can be trusted – the record reliability represents the information that was actually used in, or created by, the business process, and its integrity and authenticity can be demonstrated.
* 4.1 Part of records management involves ensuring records are of sufficient quality. To ensure the CCG has good quality data it must be:
  + Complete (in terms of having been captured in full).
  + Accurate (the data must be recorded factually, legibly and consistently).
  + Relevant (the degree to which the data meets current and potential user’s needs).
* 4.2 Good quality data will be used by the CCG to support risk minimisation, clinical and corporate governance and ultimately effective patient care. This will be achieved by setting and meeting the standards contained within this policy and ensuring all staff are aware of their responsibilities regarding data quality.
* 5.1 All NHS records are Public Records under the Public Records Acts.
* 5.2 Nurses doctors and other clinicians (such as physiotherapists) will also have professional obligations under bodies such as the Nursing and Midwifery Council (NMC) and General Medical Council (GMC) who they are accountable to. Their Codes contain professional standards that registered clinicians (such as nurses and doctors) must uphold which include details on keeping clear and accurate records.
* 6.2 All CCG staff, whether clinical or administrative, who create, receive and use clinical or corporate records have records management responsibilities. In particular all staff must ensure that they keep appropriate records of their work in the CCG and manage those records in keeping with this policy, national guidance and the Law.
* Corporate and clinical records should:
  + Be accurate and complete.
  + Be relevant and accessible.
  + Should be sufficient to enable other members of staff to carry out their tasks.
  + Should demonstrate compliance with legal and regulatory requirements.
* Access to clinical records should be on a strict need to know basis by staff that have a legitimate purpose to access such records.

**CONSENT AND RECORD KEEPING**

[**WHCCG: Fair Processing Notice**](#_top)

* Personal confidential information may also be used in the following cases:
  + The information is necessary for your direct healthcare needs.
  + You have freely given your informed agreement (consent) for us to use your information for a specific purpose.
* Within the health sector, we also have to follow the common law duty of confidence...
* Everyone working for the NHS has a legal duty to keep information about you confidential. The NHS Care Record Guarantee, <http://systems.digital.nhs.uk/rasmartcards/strategy/nhscrg> and NHS Constitution provide a commitment that all NHS organisations and those providing care on behalf of the NHS will use records about you in ways that respect your rights and promote your health and wellbeing.
* The NHS Digital Code of Practice on Confidential Information applies to all of our staff, and they are required to protect your information, inform you of how your information will be used, and allow you to decide if and how your information can be shared. All CCG staff are expected to make sure information is kept confidential and receive annual training on how to do this. This is monitored by the CCG and can be enforced through disciplinary procedures.
* Where information from which you can be identified is held by the CCG, you have the right to ask to:
  + Request information is corrected.

**CONSENT AND RECORD KEEPING**

[**WHCCG: Confidentiality Policy – Data Protection Act 1998**](#_top)

* Summary of key points to note.
  + Staff have a legal duty of confidence to keep personal confidential data private and not to divulge information accidentally. Staff may be held personally liable for a breach of confidence. Monetary penalties of up to £500k could be imposed upon the CCG, and/or employees, for non-compliance with relevant legislation and NHS guidance.
* Introduction.
  + 1.1 The NHS West Hampshire Clinical Commissioning Group (CCG) has a legal obligation to comply with all appropriate legislation in respect of confidentiality, data, information and IT security. It also has a duty to comply with guidance issued by NHS England, the Information Commissioner, other advisory groups to the NHS and guidance issued by professional bodies.
* Disclosure of information and information in transit.
  + 10.1 It is important that information about identifiable individuals (such as the general public and/or staff) should only be disclosed on a strict need to know basis. Strict controls governing the disclosure of identifiable information is also a requirement of the Caldicott recommendations.
* Disciplinary.
  + 15.1 A breach of the data protection requirements could result in a member of staff facing disciplinary action.
* Disclosure of personal and confidential information
  + 17.1 To ensure that information is shared appropriately, care must be taken to check that there is a firm legal basis in place.
  + 17.3 Information can be disclosed where consent (from the individual to whom the information relates) has been obtained.
* Staff responsibilities.
  + 19.1 All staff have a legal duty of confidence to keep personal confidential data private and not to divulge information accidentally.
* Abuse of privilege.
  + 20.1 It is strictly forbidden for employees to knowingly browse, search for or look at any information relating to themselves, their own family, friends or other person, without a legitimate purpose. Action of this kind will be viewed as breach of confidentiality and the Data Protection Act.

**CONSENT AND RECORD KEEPING**

[**WHCCG: Information Governance Staff Handbook**](#_top)

* Introduction.
  + 1.3 Information governance enables organisations to embed policies and processes to ensure that personal and sensitive information is:
    - Held securely and confidentially.
    - Obtained fairly and efficiently.
    - Recorded accurately and reliably.
    - Used effectively and ethically.
    - Shared appropriately and lawfully.
* Caldicott and Data Protection Act principles.
  + 4.1.1 All NHS employees must be aware of the seven Caldicott principles which apply to both patient and staff data.
  + 4.2 All organisations in the country must comply with the Data Protection Act 1998. Data protection law is enforced in the UK by the Information Commissioner’s Office (ICO) and has the power to fine organisations up to £500,000 for data protection breaches.
  + 4.2.2 These Data Protection and Caldicott principles translate into **key rules for all staff to follow:**
    - Patients and staff should be fully informed about how their information may be used.
    - There are strict conditions under which personal, personal confidential and sensitive data may be disclosed.
    - Individuals have the right to see what information is held about them, and to have any errors corrected.
    - Personal data should be kept secure and confidential at all times.
* Guide to confidentiality.
  + 6.2 **The common law of duty of confidentiality** requires that information that has been provided in confidence may be disclosed only for the purposes that the subject has been informed about and has consented to, unless there is a statutory or court order requirement to do otherwise.
  + 6.6.2 Under **current legislation** commissioners can only process or have access to personal confidential data if:
    - Consent has been obtained from the individual, or
    - The data has been anonymised, or
    - The data is in respect of safety, safeguarding or in the public interest.
* 6.7.3 Ensuring authorised access only.
  + Access to records will be on a ‘need to know’ basis only.
* 6.7.4 Accuracy, retention and disposal.
  + If adding information to records, ensure accuracy and relevance.
* Records management.
  + 11.2 Records management is crucial to all NHS organisations. If records are not managed effectively, the organisation would not be able to function as required and expected, and to account for what has happened in the past or to make decisions about the future. Records are a fundamental corporate asset and are required to provide evidence of actions and decision, enable the organisation to be accountable and transparent, and comply with legal and regulatory obligations such as the Data Protection Act 1998 and the Freedom of Information Act 2000.

**CONSENT AND RECORD KEEPING**

[**WHCCG: Information Governance Policy**](#_top)

* Introduction.
  + 1.4 The aims of this document are to maximise the value or organisational assets by ensuring that information is:
    - Held securely and confidentially.
    - Obtained fairly and efficiently.
    - Recorded accurately and reliably.
    - Used effectively and ethically.
    - Shared appropriately and lawfully.
  + 1.5 To protect the organisation’s information assets from all threats, whether internal or external, deliberate or accidental. The CCG will ensure:
    - Information will be protected against unauthorised access.
    - Confidentiality of information will be assured.
    - Integrity of information will be maintained.
    - Regulatory and legislative requirements will be met.
    - All breaches of information security, actual or suspected, will be reported to and investigated by the South, Central & West Commissioning Support Unit (SCW CSU) Information Governance Team.
* Scope and definitions.
  + 2.3 There are four key interlinked strands to the information governance policy:
    - Openness.
    - Legal compliance.
    - Information security.
    - Quality assurance.
* Legal compliance.
  + 4.2 The CCG will establish and maintain policies to ensure compliance with the Data Protection Act, Human Rights Act and the common law duty of confidentiality.
* Responsibilities.
  + 8.3 CCG Caldicott Guardian.
    - 8.3.1 The CCG Caldicott Guardian is seen as the ‘conscience’ of the organisation regarding the use of personal confidential data. They are responsible for ensuring all personal confidential data is shared in an appropriate and secure manner.
  + 8.10 CCG Service Leads
    - 8.10.1 Service leads are responsible for ensuring that the policy and its supporting standards and guidelines are built into local processes and that there is on-going compliance.
  + 8.11 CCG Staff
    - 8.11.1 All staff, whether permanent, temporary, contracted, or contractors are responsible for ensuring that they are aware of the requirements of this policy and for ensuring that they comply with these of a day to day basis.

**CONSENT AND RECORD KEEPING**

[**Data Protection Act 1998**](#_top)

* Part II – Rights of data subjects and others.
  + 7.1 Subject to the following provisions of this section and to sections 8 and 9, an individual is entitled-
    - To be informed by any data controller whether personal data of which that individual is the data subject are being processed by or on behalf of that data controller.
    - If that is the case, to be given by the data controller a description of-
* (i) The personal data of which that individual is the data subject
* (ii) The purposes for which they are being or are to be processed, and
* (iii) The recipients or classes of recipients to whom they are or may be disclosed.
* 13.1 An individual who suffers damage by reason of any contravention by a data controller of any of the requirements of this Act is entitled to compensation from the data controller for that damage.
* 13.2 An individual who suffers distress by reason of any contravention by a data controller of any of the requirements of this Act is entitled to compensation from the data controller for that distress if-
  + The individual also suffers damage by reason of the contravention, or
  + The contravention relates to the processing of personal data for the special purposes.
* 14.1 If a court is satisfied on the application of a data subject that personal data of which the applicant is the subject are inaccurate, the court may order the data controller to rectify, block, erase or destroy those data and any other personal data in respect of which he is the data controller and which contain an expression of opinion which appears to the court to be based on the inaccurate data.
* 14.4 If a court is satisfied on the application of a data subject-
  + (a) That he has suffered damage by reason of any contravention by a data controller of any of the requirements of this Act in respect of any personal data, in circumstances entitling him to compensation under section 13, and
  + (b) That there is a substantial risk of further contravention in respect of those data in such circumstances,

the court may order the rectification , blocking, erasure or destruction of any of those data.

* Part V – Enforcement.
  + 40.2 In deciding whether to serve an enforcement notice, the Commissioner shall consider whether the contravention has caused or is likely to cause any person damage or distress.
  + 40.3 An enforcement notice in respect of a contravention of the fourth data protection principle which requires the data controller to rectify, block, erase or destroy any inaccurate data held by him and containing an expression of opinion which appears to the Commissioner to be based on the inaccurate data.
* Part VI – Miscellaneous and general.
  + 55 Unlawful obtaining etc. of personal data.
    - 55.1 A person must not knowingly or recklessly, without the consent of the data controller-
      * (a) Obtain or disclose personal data or the information contained in personal data, or
      * (b) Procure the disclosure to another person of the information contained in personal data
    - 55.3 A person who contravenes subsection (1) is guilty of an offence.
  + 60 General provisions relating to offences.
    - 60.2 A person guilty of an offence under any provision of this Act other than paragraph 12 of Schedule 9 is liable-
      * (a) On summary conviction, to a fine not exceeding the statutory maximum, or
      * (b) On conviction on indictment, to a fine
    - 60.4 Subject to subsection (5), the court by or before which a person is convicted of-
      * (a) An offence under section 21(1), 22(6), 55 or 56,
      * (b) An offence under section 21(2) relating to processing which is assessable processing for the purposes of section 22, or
      * (c) An offence under section 47(1) relating to an enforcement notice,

may order any document or other material used in connection with the processing of personal data and appearing to the court to be connected with the commission of the offence to be forfeited, destroyed or erased.

* 61.1 Where an offence under this Act has been committed by a body corporate and is proved to have been committed with the consent or connivance of or to be attributable to any neglect on the part of any director, manager, secretary or similar officer of the body corporate or any person who was purporting to act in any such capacity, he as well as the body corporate shall be guilty of that offence and be liable to be proceeded against and punished accordingly.
* Schedule 1 – The Data Protection Principles – Part I: The Principles.
* 1 Personal data shall be processed fairly and lawfully and, in particular, shall not be processed unless-
  + (a) At least one of the conditions in Schedule 2 is met, and
  + (b) In the case of sensitive personal data, at least one of the conditions in Schedule 3 is also met.
* 2 Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.
* 3 Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposed for which they are processed.
* 4 Personal data shall be accurate and, where necessary, kept up to date.
* 6 Personal data shall be processed in accordance with the rights of data subjects under this Act.
* 7 Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.
* Schedule 1 The Data Protection Principles – Part II: Interpretation of the Principles in Part I.
  + The First Principle.
    - 1.1 In determining for the purposes of the first principle whether personal data are processed fairly, regard is to be had to the method by which they are obtained, including in particular whether any person from whom they are obtained is deceived or misled as to the purpose or purposes for which they are to be processed.
  + The Seventh Principle.
    - 10 The data controller must take reasonable steps to ensure the reliability of any employees of his who have access to the personal data.
* Schedule 2 – Conditions relevant for purposes of the first principle: Processing of any personal data.
  + 1 The data subject has given his consent to the processing.
  + 2 The processing is necessary-
    - (a) For the performance of a contract to which the data subject is a party, or
    - (b) For the taking of steps at the request of the data subject with a view to entering into a contract.
  + 3 The processing is necessary for compliance with any legal obligation to which the data controller is subject, other than an obligation imposed by contract.
  + 4 The processing is necessary in order to protect the vital interests of the data subject.
  + 5 The processing is necessary-
    - (a) For the administration of justice,
    - (b) For the exercise of any functions conferred on any person by or under any enactment,
    - (c) For the exercise of any functions of the Crown, a Minister of the Crown or a government department, or
    - (d) For the exercise of any other functions of a public nature exercised in the public interest by any person.
  + 6.1 The processing is necessary for the purposes of legitimate interests pursued by the data controller or by the third party or parties to whom the data are disclosed, except where the processing is unwarranted in any particular case by reason of prejudice to the rights and freedoms or legitimate interest of the data subject.
  + 6.2 The Secretary of State may by order specify particular circumstances in which this condition is, or is not, to be taken to be satisfied.

**CONSENT AND RECORD KEEPING**

[**Department of Health: Confidentiality – NHS Code of Practice**](#_top)

* The NHS is committed to the delivery of a first class confidential service. This means ensuring that all patient information is processed fairly, lawfully and as transparently as possible so that the public:
  + Give their consent for the disclosure and use of their personal information.
  + Gain trust in the way the NHS handles information.
* A duty of confidence arises then one person discloses information to another (e.g. patient to clinician) in circumstances where it is reasonable to expect that the information will be held in confidence. It –
  + Is a legal obligation that is derived from case law.
  + Is a requirement established within professional codes of conduct.
  + Must be included within NHS employment contract as a specific requirement linked to disciplinary procedures.
* [Patients] have the legitimate expectation that staff will respect their privacy and act appropriately.
* Information provided in confidence should not be used or disclosed in a form that might identify a patient without his or her consent.
* Whilst patients may understand that information needs to be shared between members of care teams and between different organisations involved in healthcare provision, this may not be the case and the efforts made to inform them reflect the breadth of the required disclosure.
* Consider whether patients would be surprised to learn that their information was being used in a particular way – if so, then they are not being effectively informed.
* In order to inform patients properly, staff must:
  + Make clear to patients when information is recorded or health records are accessed.
  + Make clear to patients when they are or will be disclosing information with others.
  + Check that patients have no concerns or queries about how their information is disclosed and used.
* Staff must ask patients before using their personal information in ways that do not directly contribute to, or support the delivery of, their care.
* The disclosure and use of confidential patient information needs to be both lawful and ethical.
* Common Law of Confidentiality
  + The key principle is that information confided should not be used or disclosed further, except as originally understood by the confider, or with their subsequent permission.
* Administrative Law
  + According to well-established rules a public authority must process the power to carry out what it intends to do. If not, its action is *“ultra vires”*, i.e. beyond its lawful powers
* Key Questions for Confidentiality Decisions
  + Is disclosure either a statutory requirement or required by order of a court?
  + Is the disclosure needed to support the provision of healthcare or to assure the quality of that care?
  + Have appropriate steps been taken to inform patients about proposed disclosures?
* Providing a Confidential Service: Detailed Requirements.
  + A1 Protect Patient Information.
    - Recognising that confidentiality is an obligation for all staff.
* Breach of confidence, inappropriate us of health records or abuse of computer systems may lead to disciplinary measures, bring into question professional registration and possibly result in legal proceedings.
  + - Recording patient information accurately and consistently.
* Maintaining proper records is vital to patient care. If records are inaccurate, future decisions may be wrong and harm the patient.
  + - Patient records should:
* Be factual, consistent and accurate.
* Be written, wherever applicable, with the involvement of the patient or carer.
* Be clear, unambiguous.
* Provide evidence of actions agreed with the patient (including consent to treatment and/or consent to disclose information).
* Include facts presented to the patient.
* Include correspondence from the patient or other parties.
  + A2 Inform Patients Effectively – No Surprises.
    - Make clear to patients when information is recorded or health records are accessed.
    - Make clear to patients when information is or may be disclosed to others.
    - Check that patients have no concerns or queries about how their information is used.
* Confidentiality Decisions.
  + Model B1 – where it is proposed to share confidential information in order to provide healthcare.
    - Is there a statutory requirement for, or a court order demanding, disclosure? No –
    - Is the use or sharing intended to support or audit the provision of “healthcare” to the patient concerned? Yes –
    - Is the patient competent to understand and give consent to proposed information sharing, or is someone with parental responsibility able to consent? Yes –
    - Has the patient concerned been made aware of who may see what information for what purposes and his/her right to object? No – [Yes, go to final bullet point]
    - Inform the patient about who may need to see what for information for purposes of his/her right to object.
    - Has the patient raised any concerns or objections?
* Health records are for healthcare
  + It is still very important that reasonable efforts are made to ensure that patients understand how their information is to be used to support their healthcare and that they have no objections.
* Informing patients.
  + The Data Protection Act 1998 requires that patients be informed, in general terms, how their information may be used, who will have access to it and the organisations it may be disclosed to.
* Common Law and disclosure in the Public Interest.
  + The key principle of the duty of confidence is that information confided should not be used or disclosed further in an identifiable form, except as originally understood by the confider, or with his or her subsequent permission. NHS organisations should have, or be putting in place, procedures for reviewing the appropriateness and necessity of using confidential patient information to support specific purposes. They should also be developing staff codes of practice and putting in place information sharing protocols to govern working across organisational boundaries.

**CONSENT AND RECORD KEEPING**

[**NHS England: Confidentiality Policy**](#_top)

* Staff should note that they are bound by the Confidentiality: NHS Code of Practice 2003.
* Any breach of confidentiality, inappropriate use of health records… is a disciplinary offence, which could result in dismissal or termination of employment contract, and must be reported.
* Access to person-identifiable or confidential information must be on a need-to-know basis.
* Disclosure of person-identifiable or confidential information must be limited to that purpose for which it is required.
* If the decision is taken to disclose information, that decision must be justified and documented.
* Your Contract of Employment includes a commitment to confidentiality. Breaches of confidentiality could be regarded as gross misconduct and may result in serious disciplinary action up to and including dismissal.
* Care must be taken to check they have a legal basis for access to the information before releasing it.
* It is strictly forbidden for employees to knowingly browse, search for or look at any personal or confidential information relating to themselves, their own family, friends or other persons, without a legitimate purpose. Action of this kind will be viewed as a breach of confidentiality and of the Data Protection Act.
* Don’t share information without the consent of the person to which the information relates, unless there are statutory grounds to do so.
* The NHS Care Record Guarantee – Commitment 3
  + We will not share information that identifies you for any reason, unless
    - You ask us to do so.
    - We ask and you give us specific permission.
    - We have to do this by law.
    - We have special permission for health or research purposes
* Unauthorised access to person-identifiable information where the member of staff does not have a need to know.

**CONSENT AND RECORD KEEPING**

[**NHS: The Care Record Guarantee**](#_top)

* We have a duty to:
  + Maintain accurate records.
  + Keep records about you confidential, secure and accurate.
* It is good practice for people in the NHS who provide your care to:
  + Discuss and agree with you what they are going to record about you.
* Our 12 commitments to you.
  + 2 We will aim to share only as much information as people need to know to play their part in your healthcare.
  + 3 We will not share health information that identifies you for any reason other than providing your care, unless:
    - You ask us to do so.
    - We ask and you give us specific permission.
    - We have to do this by law.
  + 4 Legally, no-one else can make decisions on your behalf about sharing health information that identifies you.
  + 6 Usually you can choose to limit how we share the information in you care records which identifies you. In helping you decide, we will discuss with you how this may affect our ability to provide you with care or treatment, and any alternatives available to you.
  + 7 We will have a clear complaints procedure.
  + 8 We will take appropriate steps to make sure information about you is accurate. You will be given opportunities to check records about you and point out mistakes. We will normally correct factual mistakes. If you are not happy with an opinion or comment that has been recorded, we will add your comments to the record. If you feel you are suffering distress or harm as a result of information currently held in your record, you can apply to have the information amended or deleted.
  + 12 If you believe your information is being viewed inappropriately we will investigate and report our findings to you. If we find that someone has deliberately accessed records about you without permission or good reason, we will tell you and take action. This can include disciplinary action, which could include ending a contract, firing an employee or bringing criminal charges.
* Six things you can do in return.
  + Tell us if any information in your record is wrong.

**CONSENT AND RECORD KEEPING**

[**The Caldicott Principles**](#_top)

* Principle 1 – Justify the purpose for using confidential information.
  + Every proposed use or transfer of personal confidential data within or from an organisation should be clearly defined, scrutinised and documented, with continuing uses regularly reviewed, by an appropriate guardian.
* Principle 2 – Don’t use personal confidential data unless it is absolutely necessary.
  + Personal confidential data items should not be included unless it is essential for the specified purpose(s) of that flow. The need for patients to be identified should be considered at each stage of satisfying the purpose(s).
* Principle 4 – Access to personal confidential data should be on a strict need-to-know basis.
  + Only those individuals who need access to personal confidential data should have access to it, and they should only have access to the data items that they need to see.
* Principle 5 – Everyone with access to personal confidential data should be aware of their responsibilities.
  + Action should be taken to ensure that those handling personal confidential data – both clinical and non-clinical staff – are made fully aware of their responsibilities and obligations to respect patient confidentiality.
* Principle 6 – Comply with the law.
  + Every use of personal confidential data must be lawful. Someone in each organisation handling personal confidential data should be responsible for ensuring that the organisation complies with legal requirements.

**CONSENT AND RECORD KEEPING**

[**ICO: The Guide to Data Protection**](#_top)

* For the purposes of this Act [Data Protection] data are inaccurate if they are incorrect or misleading as to any matter of fact.
* Personal data may not be inaccurate if it faithfully represents someone’s opinion about an individual, even if the opinion proves incorrect. In these circumstances, the data would not need to be “corrected”, but the data controller may have to add a note stating that the data subject disagrees with the opinion.
* Data Protection Act Principle 1 – Fair and lawful
  + Processing data must above all else be fair.
  + “Processing” broadly means collecting, using, disclosing, retaining or disposing of personal data, and if any aspect of processing is unfair, there will be a breach of the first data protection principle.
  + Fairness generally requires you to be transparent – clear and open with individuals about how their information will be used.
  + Processing may also be unlawful if it results in:
    - A breach of industry-specific legislation or regulations.
* Data Protection Act Principle 2 – Purposes
  + The second data protection principle means that you must:
    - Be clear from the outset about why you are collecting personal data and what you intend to do with it.
    - Comply with the Act’s fair processing requirements.
    - Ensure that if you wish to use or disclose the personal data for any purpose that is additional to or different from the originally specified purpose, the new use or disclosure is fair.
* Data Protection Act Principle 4 – Personal data shall be accurate and where necessary, kept up to date.
  + To comply with these provisions you should
    - Take reasonable steps to ensure the accuracy of any personal data you obtain.
    - Ensure that the source of any personal data is clear.
    - Carefully consider any challenges to the accuracy of information.
    - Consider whether it is necessary to update the information.
  + The more important it is that the personal data is accurate, the greater the effort you should put into ensuring its accuracy.
  + What happens when individuals challenge the accuracy of information held about them?
    - If this happens, you should consider whether the information is accurate and, if it is not, you should delete or correct it.
    - Sometimes the individual may be able to provide convincing documentary evidence.
    - In other circumstances, you may need to make some checks yourself.
  + Where the accuracy of a record has been challenged by the individual it relates to, it is good practice to mark the record as being in dispute.
  + The advantage of flagging a disputed record is that it avoids you breaching the fourth data protection principle if the information does turn out to be inaccurate.
  + If an individual is not satisfied that you have taken appropriate action to keep their personal data accurate, they may apply to the court for an order that you rectify, block, erase or destroy the inaccurate information.
* Compensation
  + In 2015 the Court of Appeal ruled, in the case of Vidal-Hall v Google, that compensation under the DPA could be awarded for distress alone.

**CONSENT AND RECORD KEEPING**

[**IGA: Records Management Code of Practice for Health and Social Care 2016**](#_top)

* For most professionals working in health and social care, there are relevant codes of practice issued by the registration bodies and membership organisation of staff. That guidance is designed to guard against professional misconduct and to provide high quality care in line with professional bodies.
* The DPA is the principle legislation governing how care records are managed. The DPA principles are:
  + 1 Personal information must be fairly and lawfully processed.
  + 4 Personal information must be accurate and up to date.
  + 6 Personal information must be processed in line with the data subjects’ rights.
* The Caldicott principles outline seven areas that all health and social care staff are expected to adhere to in addition to the DPA. These principles are:
  + 1 Justify the purpose(s).
  + 2 Don’t use personal confidential data unless it is absolutely necessary.
  + 4 Access to personal confidential data should be on a strict need-to-know basis.
  + 6 Comply with the law.
* The NHS and Social Care ‘Care Records Guarantees’ outline twelve guarantees that record keeping must adhere to
* Under the Public Records Act 1958 employees are responsible for any records that they create or use in the course of their duties.
* Each organisation should have an overall policy statement on how it manages all of its records. The policy should also:
  + Define roles and responsibilities within the organisation, including the responsibility of individuals to document their actions and decisions in the organisation’s records.
* Characteristics of authoritative records (derived from Section 5.2 – ISO15489-1:2016).
  + Reliable – Full and accurate record of the transaction/activity or fact.
  + Integrity – Complete and unaltered.
  + Useable – The context can be established through links to other records in the transaction/activity.
* Where a patient or client complains about a service, it is necessary to keep a separate file relating to the complaint and subsequent investigation. Complaint information should never be recorded in the clinical record.
* Where multiple teams are involved in the complaint handling, all the associated records must be amalgamated to form a single record. It is common for the patient or client to ask to see a copy of their complaint file and it will be easier to deal with if all relevant material is in one file.
* In order to process applications and appeals for funding continuing care, it is necessary for the relevant organisation to have access to clinical records. This will be based on consent. Any access must be lawful and the decision to grant access recorded.

**CONSENT AND RECORD KEEPING**

[**NMC: Record Keeping – Guidance for Nurses and Midwives**](#_top)

* + 10 – You must not alter or destroy any records without being authorised to do so.
  + 12 – Where appropriate, the person in your care, or their carer, should be involved in the record keeping process.
  + 16 – You should not falsify records.
  + 32 – You have a duty to keep up to date with, and adhere to, relevant legislation, case law, and national and local policies relating to information and record keeping.

**CONSENT AND RECORD KEEPING**

[**What is the Law on Patient Consent?**](#_top)

* The law does not set any time-scale for the validity of a form of consent signed by the patient. The form is, in fact, not the actual consent but evidence that the patient is consenting to a particular procedure at a given time.
* The patient is entitled to change her or his mind. The law requires that a patient is mentally capable and understands the nature of the procedure, that the consent is voluntary and there is no coercion or inducement that has been of influence in obtaining the consent. Also, any significant information relating to the serious risk of substantial harm must have been given to the patient.
* In applying the law, the most important question is – what are the patient’s views at present? Although the patient has signed a form, rather than rely on this, it would be easy to check with the patient her or his current views. If the patient is still consenting to the surgery, then a note to the fact can be added to the form.
* The note should specify the date on which that continuing consent was checked.
* If there are worries of concern to the patient, then these can be discussed and resolved and again a note to the effect added to the form. The patient could be asked to put her or his name to that note.
* It is, in law, possible to rely on a signed form of consent as being still operative, as long as it would appear to be reasonable that it is still valid. However, any lengthy delay between the form being signed and the treatment, any sign that the patient has concerns or might have changed her or his mind, or any other indication that reliance should not be placed on the written consent, should be followed up by discussions with the patient. In the case of doubt, check with the patient again.
* The Kennedy Report, following the inquiry into the Bristol paediatric heart surgery, made significant recommendations in relation to obtaining consent.
* *Bridgit Dimond, MA, LLB, DASA, AHSA, is barrister-at-law and emeritus professor, University of Glamorgan, Pontypridd*

**CONSENT AND RECORD KEEPING**

[**Consent to Screening and Assessment for NHS Continuing Healthcare 2010**](#_top)

* Consent form signed on 16th September 2010.
  + I have received written information on both the Continuing Healthcare Process and the Appeal Pathway. This has been explained to me and I am aware that I can withdraw consent at any time.
  + I agree to an NHS Continuing Healthcare Checklist, Fast Track Pathway, Decision Support Tool and all subsequent reviews being undertaken.
  + I agree to relevant information being gathered, collated and shared, where necessary and relevant, both as part of the PCT NHS Continuing Healthcare process and also, as part of any dispute process which may occur, to include the preparation of the case file for the PCT and for Independent Review Panel at the Strategic Health Authority / Parliamentary and Health Service Ombudsman (PHSO).
  + I agree that the information provided in this assessment may be shared with Health and Social Care staff, Service Providers who contribute to my care and any agencies acting on behalf of these organisations for the purpose / process relating to NHS Continuing Healthcare.
  + I understand that this information will be used in the assessment of my eligibility for NHS Continuing Healthcare funding and may be used for the purpose of providing a service, or care to me.
  + I understand that I may withdraw my consent to share information at any time.
  + I understand that I have the right to restrict what information may be shared and with whom but that this may affect the provision of care to me.
* Consent based upon 2007 Continuing Healthcare Framework (updated 2010).
* Due to \_\_\_’s cognitive impairment, she has no recollection of the content of this form nor signing it.

**CARE PACKAGE**

[**NHS CHC National Framework**](#_top)

* + 33. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual’s assessed health and social care needs.
  + PG89. 1 When a CCG decides to support a home-based package where the involvement of a family member/friend is an integral part of the care plan then the CCG should give consideration to meeting any training needs that the carer may have to carry out this role. In particular, the CCG may need to provide additional support to care for the individual whilst the carer(s) has a break from his/her caring responsibilities and will need to assure carers of the availability of this support when required. This could take the form of the cared-for person receiving additional services in their own home.

**CARE PACKAGE**

[**WHCCG and HCC Joint Operational Policy v4**](#_top)

* + 12. 1 Case reviews will be undertaken for individuals no later than three months following the eligibility decision and thereafter on an annual basis, unless a change in need or circumstance identifies an earlier review is required. This will ensure that individual is receiving the care they need and that they remain eligible for NHS CHC funding. Should a review show that following a change in need the individual may no longer meets criteria then a reassessment of eligibility must be undertaken following the DST process.

**CARE PACKAGE**

[**Involving People in Their Own Health and Care: Statutory Guidance for CCGs and NHS England**](#_top)

* It is a legal duty.
* Promoting the involvement of people in their own health and care is a key component of CCGs’ and NHS England’s statutory duties.
* Section 4U of the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012) specifically states that CCGs must promote involvement of each individual, their carer and (should there be any) their representatives in decisions relating to prevention or diagnosis of illness, or their care or treatment.
* The landmark Supreme Court case of Montgomery v Lanarkshire Health Board [2015] UKSC 11 confirms that:
  + The doctor is under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in proposed treatment, and of reasonable alternatives.
  + A risk is ‘material’ if a reasonable person in the patient’s position would be likely to attach significance to it, or if the doctor is or should be reasonably be aware that their patient would be likely to attach significance to it.
* The NHS Standard Contract 2017/18 and 2018/19 requires providers to provide clear information to service users, that questions are responded to promptly and effectively and actively engage, liaise and communicate with service users in an open and clear manner in accordance with the law and good practice (Service Condition 12).

**CARE PACKAGE**

[**DoH: Independence, Choice and Risk – A Guide to Best Practice in Supported Decision Making**](#_top)

* 1.2 What needs to be considered is the consequence of an action and the likelihood of any harm from it.
* 1.3 A decision about the perceived or actual risk needs to be taken in conjunction with the person using services themselves, as well as the professionals involved.
* 2.24 Our legal system is concerned with concepts of negligence, abuse and foreseeability of harm.
* 2.24 The human rights of people must underpin the actions and decisions of all public authorities.
* 2.27 Providers and/or commissioners could, however, be exposed to litigation if they place people in a position of risk.

**COMPLAINTS**

[**WHCCG Complaints Policy**](#_top)

* + 1.1 West Hampshire CCG is committed to providing an accessible and impartial complaints service to those people personally affected by services provided.
  + 1.5 It is essential that all complaints… are investigated thoroughly and promptly, and responded to in an open and sympathetic manner, with action taken, where appropriate, to prevent a recurrence of the circumstances leading to the complaint.
  + 1.6 Complainants will therefore be invited to discuss the handling of their complaint in person or by telephone to agree a timescale and confirm their desired outcome.
  + 2.1.3 West Hampshire CCG is committed to meeting the standards laid down in these Regulations. It will provide an accessible and impartial complaints service. It will respond actively and positively in a timely and effective manner from complaints and implement changes to prevent problems from recurring.
  + 3.6.3 At the time of acknowledging the complaint the complaints team must offer to discuss and agree a plan of action with the complainant for handling the complaint which includes:
    - When the investigation is likely to be completed
    - What reasonable outcome is desired.
    - When the response is likely to be sent.
    - Offer an early meeting if appropriate.
    - What the issues are that the complainant wants raised / addressed.
  + 3.6.4 The agreed actions, questions and timescales for response will be confirmed in writing to the complainant.
  + 3.9.1 The investigation into a complaint must:
    - Be undertaken by a suitable person.
  + 3.10.1 The CCG will send a formal response in writing to the complainant which will be signed by the Chief Officer or nominated responsible person.
  + 3.10.2 The response will also:
    - Offer an explanation of how the complaint has been investigated, address the concerns expressed by the complainant and show that each element has been fully and fairly investigated.
  + 3.10.8 All statements, letters, phone calls and actions taken in an investigation must be documented and kept in the complaint file in chronological order.
  + 3.18.1 The PHSO (Parliamentary and Health Service Ombudsman) have published the Principles of Good Complaints Handling which encompasses:
    - Getting it right.
    - Being customer focused.
    - Being open and accountable.
    - Acting fairly and proportionally.
    - Putting things right.
    - Seeking continuous improvement.
  + 3.21.3 The Clinical Governance Committee (CGC) will receive quarterly reports as part of governance and performance reporting. The reports will identify any trends and patterns arising from complaints, and any subsequent action taken as a result of lessons learned.
  + 3.21.4 An annual report will be prepared for the CGC on the handling and consideration of complaints, outlining actions, monitoring compliance and outcomes. This should include:
    - Each complaint received.
    - The subject matter of each complaint – some will involve several issues.
    - The outcome of each complaint / issue (whether it is well founded or not).
    - The agreed timeframe to respond to the complaint and any extensions agreed.
    - Number of complaints received.
    - Number of complaints found to be well founded / upheld.
    - Number of complaints referred to the Health Service Ombudsman.
  + 3.21.5 In addition to this, summarise:-
    - Subject matter of complaints; Any matters of importance arising out of the complaints, or the way in which they were handled.
    - Any matters where action has been or is to be taken to improve services as a result of the complaint.
  + 3.21.6 It is important that lessons are learnt from a complaint… Staff will be held accountable if a complaint is upheld against any of their actions.
  + 3.21.7 Complaint reports will be made available on the West Hampshire CCG website.
  + 4.1.2 It is the responsibility of all directorates and teams to adhere to the Complaints Policy.
  + 4.1.3 Staff will be made aware of the complaint and asked to prepare written or verbal statements as part of the investigation.
  + 4.2.1 The Chief Officer is responsible for ensuring compliance with the arrangements under the Local Authority Social Services and NHS Complaints (England) Regulations 2009, and in particular ensuring that action is taken if necessary in the light of the outcome of a complaint.
  + 4.2.2 The Director of Quality (Board Nurse) is responsible for overseeing the complaints management process, ensuring that complaints are handled in accordance with the policy.
  + 4.2.3.2 The Patient Experience and Complaints Manager/s will co-ordinate and collate all the information required in order to produce a response to the complainant.
  + 4.2.4 The investigator is responsible for undertaking the detailed investigation of complaints, to provide information in order that the Patient Experience and Complaints Manager/s can draft the written response for review by the director of the service, prior to signature by the Chief Officer or nominated director.
  + 4.2.5 Managers are responsible for ensuring that complaints are investigated in accordance with this policy.
  + 5.1 All staff will be expected to have a working knowledge of the Complaints Procedure and will be familiarised with this policy as part of their induction.
  + 5.4 Investigators will require a higher level of complaints training to ensure a though [sic] and comprehensive investigation and response.
  + Appendix 5
    - The underlying approach promoted by the Principles for Remedy is for the service provider to restore the complainant to the position they would have been in if the maladministration or poor service had not occurred.
    - Remedies should be fair, reasonable and proportionate to the injustice of [sic] hardship incurred.
    - Decisions to make payments should be endorsed by the CCG Director of Finance / Chief Officer. Such decisions should take into account the following factors:
* How much the complainant has demonstrably lost financially or what extra costs they have incurred.
* The impact on the individual, for example whether the events contributed to ill health or led to prolonged or aggravated injustice or hardship.
* The length of time taken to resolve a dispute or complaint.
* The trouble the individual was put to in pursuing the dispute or complaint.

**COMPLAINTS**

[**PHSO: Principles of Good Complaint Handling**](#_top)

* Prompt and efficient complaint handling can save the public body time and money by preventing a complaint from escalating unnecessarily.
* 1 Getting it right.
  + Acting in accordance with the law and the relevant guidance, and with regard for the rights of those concerned.
* 2 Being customer focused.
  + Having clear and simple procedures.
  + Dealing with complaints promptly and sensitively, bearing in mind their individual circumstances.
  + Listening to complainants to understand the complaint and the outcome they are seeking.
  + Deal with complaints promptly, avoiding unnecessary delay, and in line with published service standards where appropriate.
  + Public bodies should keep the complainant regularly informed about progress and the reasons for any delays.
  + Listen to and consider the complainant’s views, asking them to clarify where necessary, to make sure the public body understands clearly what the complaint is about and the outcome the complainant wants.
* 3 Being open and accountable.
  + Publishing service standards for handling complaints.
  + Providing honest, evidence-based explanations and giving reasons for decisions.
  + Keeping full and accurate records.
  + Create and maintain reliable and usable records as evidence of their activities. These records should include the evidence considered and the reasons for decisions.
  + Take responsibility for the actions of their staff and those acting on behalf of the public body.
* 4 Acting fairly and proportionately.
  + Ensuring that complaints are investigated thoroughly and fairly to establish the facts of the case.
  + Ensuring that the decisions are proportionate, appropriate and fair.
  + Investigate complaints thoroughly and fairly, basing their decisions on the available facts and evidence, and avoiding undue delay.
* 5 Putting things right.
  + Providing prompt, appropriate and proportionate remedies.
  + Considering all the relevant factors of the case when offering remedies.
  + Taking account of any injustice or hardship that results from pursuing the complaint as well as from the original dispute.
  + There is a wide range of appropriate response to a complaint that has been upheld. These include:
    - An apology, explanation and acknowledgement of responsibility.
    - Remedial action, which may include reviewing or changing a decision on the service given to an individual complaint; revising published material; revising procedures, policies or guidance to prevent the same thing happening again; training or supervision; or any combination of these.
    - Financial compensation for direct or indirect financial loss, loss of opportunity, inconvenience, distress, or any combination of these.
  + When deciding the level of financial compensation, public bodies should consider:
    - The nature of the complaint.
    - The impact on the complainant.
    - How long it took to resolve the complaint.
    - The trouble the complainant was put to in pursuing it.
  + Remedies may also need to take account of any injustice or hardship that has resulted from pursuing the complaint as well as from the original dispute.
* 6 Seeking continuous improvement.
  + Using all feedback and the lessons learnt from complaints to improve service design and delivery.
  + Where appropriate, telling the complainant about the lessons learnt and changes made to services, guidance or policy.

**COMPLAINTS**

[**The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009**](#_top)

* 3 Arrangements for the handling and consideration of complaints.
  + (2) The arrangements for dealing with complaints must be such that –
    - (a) Complaints are dealt with efficiently.
    - (b) Complaints are properly investigated.
    - (e) Complainants receive a timely and appropriate response.
    - (f) Complainants are told the outcome of the investigation of their complaint.
    - (g) Action is taken if necessary in the light of the outcome of a complaint.
* 13 Procedure before investigation.
  + (7) At the time it acknowledges the complaint, the responsible body must offer to discuss with the complainant, at a time to be agreed with the complainant –
    - (a) The manner in which the complaint is to be handled
    - (b) The period (“the response period”) within which –
* (i) The investigation of the complaint is likely to be completed.
* (ii) The response required by regulation 14(2) is likely to be sent to the complainant.
* 14 Investigation and response.
  + (1) A responsible body to which a complaint is made must –
    - (a) Investigate the complaint in a manner appropriate to resolve it speedily and efficiently.
    - (b) During the investigation, keep the complainant informed, as far as reasonably practicable, as to the progress of the investigation.
  + (2) The responsible body must send the complainant in writing a response, signed by the responsible person, which includes –
    - (a) A report which includes the following matters –
      * (i) An explanation of how the complaint has been considered.
      * (ii) The conclusions reached in relation to the complaint, including any matters for which the complaint specifies, or the responsible body considers, that remedial action is needed.
    - (b) Confirmation as to whether the responsible body is satisfied that any action needed in consequence of the complaint has been taken or is proposed to be taken.

**COMPLAINTS**

[**Response from \_\_\_ to Formal Complaint (10 November 2017) – Apologies**](#_top)

* + *“I apologise that the review was not carried out to the expected standard.”*
  + *“The Continuing Healthcare team are sorry that the case coordinator did not review the documentation from \_\_\_, Specialist Epilepsy Nurse, nor those provided by \_\_\_, Chief Executive Office [sic] of \_\_\_.”*
  + *“I apologise that the case coordinator’s approach was not in line with the values promoted within the NHS Continuing Healthcare team for West Hampshire Clinical Commissioning Group.”*
  + *“It is acknowledged that in this circumstance usual process [for preparing for appointments] was not followed for which the team would like to apologise.”*
  + *“The team’s Professional Lead, who undertook the complaint investigation understands the risks associated with tonic-clonic seizures, refractory epilepsy, respiratory requirements and Buccal Midazolam and that each individual will require a measured and clinically sound response dependent on clinical requirements.”*
  + *“The team will therefore respond to the training need highlighted around epilepsy care for all case coordinators.”*
  + *“The team apologise that this [decisions for DST review meetings] was not effectively completed or communicated to you at the time of the meeting.”*
  + *“Please accept our sincere apologise [sic] for any distress the review process has caused you and your family. I understand that clinical assessments of this nature generally can cause anxiety, which have been heightened by the lack of confidence in the clinical recommendations being made.”*

**COMPLAINTS**

[**PSHO: Audio Recordings and Their Role in Local NHS Complaints Resolutions**](#_top)

* In health cases, the law normally prevents us from investigating unless we are satisfied the local complaints process has been followed correctly to its final conclusion.

**MISCELLANEOUS**

[**Handbook to The NHS Constitution**](#_top)

* What legal underpinning does the constitution have?
* The Health Act 2009
* The Health and Social Care Act 2012
* The Care Act 2014
* Principle 4 – The patient will be at the heart of everything the NHS does
* Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment.
* This principle enshrines the NHS as a patient-centred service.
* It recognised the need for patients, along with their families and carers, to be involved in discussions about their care.
* The importance of individuals being involved in their own care and treatment was set out in the Health and Social Care Act 2012, which placed new duties on commissioners to do this.
* Fundamental Standards
* The fundamental standards set the line below which care and treatment must never fall.
* The fundamental standards are legal requirements.
* Patient Rights (Section 3a of the NHS Constitution)
* You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences.
  + Your care and treatment needs and preferences should be assessed by people with the required levels of skill and knowledge for the particular task.
  + Source of right – Regulation 9 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.
* You have the right not to be unlawfully discriminated against in the provision of NHS services.
  + The Equality Act 2010 makes it unlawful for a person providing services to discriminate on various grounds.
  + Individual health professionals are also governed by the standards set under the professional regulatory regime that applies to their profession.
* You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff.
  + NHS staff must treat you with reasonable care.
  + The staff who provide NHS services must be qualified and have the experience needed to do their job well.
  + The law of negligence imposes a duty of care on providers of healthcare
* You have the right to expect NHS bodies to monitor, and make efforts to improve continuously, the quality of healthcare they commission or provide. This includes improvements to the safety, effectiveness and experience of services.
  + Effectiveness of care – Domain 2: Enhancing the quality of life for people with long term conditions.
  + Patient Experience – Domain 4: Ensuring people have a positive experience of care.
  + Patient Safety – Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm.
  + National Health Service Act 2006 (as amended by the Health and Social Care Act 2012)
* You have the right to be protected from abuse and neglect, and care and treatment that is degrading.
  + People who use services must be protected from suffering any form of abuse or improper treatment, including degrading treatment or treatment which significantly disregards their needs.
  + Regulation 13 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.
* You have the right of access to your own health records and to have any factual inaccuracies corrected.
  + You have the right to see your health records.
  + You have the right to have any factual inaccuracies corrected.
  + Where you and the health professional cannot agree on whether the information in question is accurate you can ask that a statement is included to set out that the accuracy of the information is disputed by you.
* You have the right to privacy and confidentiality and to expect the NHS to keep your confidential information safe and secure.
  + NHS staff have both a professional and legal duty to keep information you provide to them confidential and to respect your privacy.
  + This does not mean that your information will not be shared but it does mean that it will only be shared with your agreement (consent) or if there is another legal basis.
* You have the right to be involved in planning and making decisions about your health and care with your provider or providers, including your end of life care, and to be given information and support to enable you to do this.
  + You should be involved as much as you want to be in discussing your needs and preferences.
  + Regulation 9 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.
* You have the right to an open and transparent relationship with the organisation providing your care.
  + This right is to ensure that providers are open and transparent with you.
  + It also sets out some specific requirements that providers must follow when things go wrong with care and treatment.
  + This includes informing you about the incident, providing truthful information and an apology when things go wrong.
  + Providers must also give all reasonable support necessary to help you overcome the physical, psychological and emotional impact of the incident.
* You have the right to have any complaint you make about NHS services acknowledged within three working days and to have it properly investigated.
  + You also have the right for that complaint to be investigated properly.
* You have the right to discuss the manner in which the complaint is to be handled.
  + If you make a complaint, you have the right to be offered a discussion about the way in which the complaint is to be handled.
* You have the right to be kept informed of progress and to know the outcome of any investigation into your complaint, including an explanation of the conclusions and confirmation that any action needed in consequence of the complaint has been taken or is proposed to be taken.
  + If you make a complaint, you have the right to be kept informed of how the investigation into that complaint is progressing.
  + When the investigation is completed, you have the right to be told the outcome; this will include an explanation of the conclusions reached and what action has been taken (or will be taken) as a result.
* You have the right to compensation where you have been harmed by negligent treatment.
  + If you have been harmed through negligent treatment, you have a right to claim for damages.
  + If this is something you want to do, you should seek legal advice.
  + Individual health professionals are governed by the standards set under the Professional regulatory regime that applies to their profession.
* Pledges (Section 3a of the NHS Constitution)
* The NHS commits to ensure those involved in your care and treatment have access to your health information so they can care for you safely and effectively.
* Where the purpose is to support your care, information about you will only be shared with your consent.
* In general, this consent will be implied as part of the consent you give to be referred to other services but you should be informed about these uses.
* The NHS commits to share with you any correspondence sent between clinicians about your care.
* The NHS commits to work in partnership with you, your family, carers and representatives.
* The updated strategy [Recognised, valued and supported: next steps for the Carers Strategy 2010] identifies four priority areas.
  + - Supporting those with caring responsibilities to identify themselves as carers.
    - Enabling those with caring responsibilities to fulfil their educational and employment potential.
    - Personalised support both for carers and those they support.
    - Supporting carers to remain mentally and physically well.
* The NHS commits to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one.
* For people with long-term conditions, the aim is to identify how your condition is impacting on the things that are important to you.
* To offer you a written record of what is agreed.
* The NHS commits to ensure that when mistakes happen or if you are harmed while receiving healthcare, you receive an appropriate apology, delivered with sensitivity and recognition of the trauma you have experienced, and know that lessons will be learned to help avoid a similar incident occurring again.
* The NHS commits to ensure that the organisation learns lessons from complaints and claims and uses these to improve NHS services.
* The pledges are consistent with the *Principles of Good Administration, Principles of Good Complaint Handling* and *Principles for Remedy*, published by the Parliamentary and Health Service Ombudsmen, which the Department of Health fully endorses.
* Duties (Section 4b of the NHS Constitution)
  + To accept professional accountability and maintain the standards of professional practice as set by the appropriate regulatory body applicable to your profession or role.
    - Action can be taken based on the policies and practices of regulatory bodies:
      * The Nursing and Midwifery Council (NMC).
* The Health and Care Professions Council (HCPC).
* To protect the confidentiality of personal information that you hold.
  + - Disciplinary action may be taken by the employer against workers who breach the confidentiality and data protection policies.
* To be honest and truthful in applying for a job and in carrying out that job.
* An employer could take disciplinary action for failure to adhere to duty of trust and confidence.
* Expectations (Section 4b of the NHS Constitution)
* You should aim to provide all patients with safe care, and to do all you can to protect patients from avoidable harm.
  + All members of staff have a personal responsibility for patient safety and individual’s needs.
  + Every person working in NHS-funded care has a duty to identify and help reduce the risks to the safety of patients.
* You should aim to follow all guidance, standards and codes relevant to your role, subject to any more specific requirements of your employers.
  + It is important to reassure patients that all NHS staff are following the required guidance, standards and codes when fulfilling their role.
* You should aim to involve patients, their families, carers or representatives fully in decisions about prevention, diagnosis, and their individual care and treatment.
  + It is important that patients are treated as equal, informed and active partners.
* You should aim to be open with patients, their families, carers or representatives, including if anything goes wrong.
  + Communicate openly, honestly and sympathetically with patients and their families, carers or representatives about their care.
  + Provide support to the patient and their families, carers or representatives to help them cope with the physical and psychological consequences of what happened.
  + Understand your organisation’s complaints procedures.
* You should aim to inform patients about the use of their confidential information and record their objections, consent or dissent.
  + As a staff member, you should aim to support patients in understanding how their confidential information is used.
  + You should record the patient’s views – any objection, consent or dissent.

**MISCELLANEOUS**

[**WHCCG: Conduct, Performance, Grievance and Absence Management Policy**](#_top)

* 4 Misconduct Examples.
  + 4.2 The following are examples of actions which constitute gross misconduct and are likely to lead to summary dismissal (this list is not exhaustive):
    - (d) Failure to comply with… important CCG rules, policies or procedures.
    - (e) Regulatory compliance: failure to comply with rules or regulatory requirements established by any regulatory body to which the CCG is subject or other conduct which causes the CCG to be in breach of its regulatory responsibilities.
    - (h) Reckless behaviour: an act of recklessness or incompetence sufficiently severe to break down trust and confidence in the employee’s ability to undertake the job.
    - (k) Gross carelessness, incompetence or negligence.
    - (l) Bringing the CCG into serious disrepute through grossly unprofessional or unbecoming behaviour or other serious action likely to bring the CCG into disrepute.
    - (m) Breach of confidence; disclosure or misuse of confidential information or data about the CCG, other CCGs in the sector, patients or staff.
    - (o) Misuse of equipment: obtaining unauthorised access to, making unauthorised use of or making unauthorised amendments to information stored on computers. Any failure to comply with… confidentiality / data protection policy.

**MISCELLANEOUS**

[**NICE: Managing Medicines for Adults Receiving Social Care in the Community**](#_top)

* 1.3.5 When specific skills are needed to give a medicine, health professionals should only delegate the task of giving the medicine to a care worker when:
  + There is local agreement between health and social care that this support will be provided by a care worker.
  + The person (or their family member or carer if they have lasting power of attorney) has given their consent.
  + The responsibilities of each person are agreed and recorded.
  + The care worker is trained and assessed as competent.

**MISCELLANEOUS**

[**NMC: The Code – Professional Standards of Practice and Behaviour for Nurses and Midwives**](#_top)

* 2 Listen to people and respond to their preferences and concerns.
  + 2.1 Work in partnership with people to make sure you deliver care effectively.
  + 2.3 Encourage and empower people to share decisions about their treatment and care.
* 3 Make sure that people’s physical, social and psychological needs are assessed and responded to.
  + 3.4 Act as an advocate for the vulnerable, challenging poor practice.
* 4 Act in the best interests of people at all times.
  + 4.2 Make sure that you get properly informed consent and document it before carrying out any action.
* 5 Respect people’s right to privacy and confidentiality.
  + 5.2 Make sure that people are informed about how and why information is used and shared by those who will be providing care.
* 6 Always practise in line with the best available evidence.
  + 6.1 Make sure that any information or advice given is evidence based.
* 10 Keep clear and accurate records relevant to your practice.
  + 10.2 Identify any risks or problems that have arisen and the steps taken to deal with them, so that colleagues who use the records have all the information they need.
  + 10.3 Complete all records accurately and without any falsification, taking immediate and appropriate action if you become aware that someone has not kept to these requirements.
  + 10.6 Collect, treat and store all data and research findings appropriately.
* 13 Recognise and work within the limits of your competence
  + 13.1 Accurately assess signs of normal or worsening physical and mental health in the person receiving care.
* 14 Be open and candid with all service users about all aspects of care and treatment, including when any mistakes or harm have taken place.
  + Act immediately to put right the situation if someone has suffered actual harm for any reason or an incident has happened which had the potential for harm.
* 15 Always offer help if an emergency arises in your practice setting or anywhere else.
* 16 Act without delay if you believe that there is a risk to patient safety or public protection.
  + 16.2 Raise your concerns immediately if you are being asked to practise beyond your role, experience and training.
  + 16.4 Acknowledge and act on all concerns raised to you, investigation, escalating or dealing with those concerns where it is appropriate for you to do so.
  + 16.5 Not obstruct, intimidate, victimise or in any way hinder a colleague, member of staff, person you care for or member of the public who wants to raise a concern.
* 17 Raise concerns immediately if you believe a person is vulnerable or at risk and needs extra support and protection.
  + 17.1 Take all reasonable steps to protect people who are vulnerable or at risk of harm.
  + 17.2 Share information if you believe someone may be at risk of harm, in line with the laws relating to the disclosure of information.
* 20 Uphold the reputation of your profession at all times.
  + 20.1 Keep to and uphold the standards and values set out in the Code.
  + 20.2 Act with honesty and integrity at all times.
  + 20.3 Be aware at all times of how your behaviour can affect and influence the behaviour of other people.
  + 20.4 Keep to the laws of the country in which you are practising.
  + 20.5 Treat people in a way that does not take advantage of their vulnerability or cause them upset or distress.
  + 20.6 Stay objective

**MISCELLANEOUS**

[**HCPC: Standards of Conduct, Performance and Ethics**](#_top)

* 1 Promote and protect the interests of service users and carers.
  + Treat service users and carers with respect.
    - 1.1 You must treat service users and carers as individuals, respecting their privacy and dignity.
    - 1.2 You must work in partnership with service users and carer, involving them, where appropriate, in decisions about the care, treatment or other services to be provided.
  + Make sure you have consent.
    - 1.4 You must make sure that you have consent from service users or other appropriate authority before you provide care, treatment or other services.
* 2 Communicate appropriately and effectively.
  + Communicate with service users and carers.
    - 2.2 You must listen to service users and carers and take account of their needs and wishes.
* 5 Respect confidentiality.
  + Using information.
    - 5.1 You must treat information about service users as confidential.
  + Disclosing information.
    - 5.2 You must only disclose confidential information if:
* You have permission.
* The law allows this.
* 6 Manage risk.
  + Identify and minimise risk.
    - 6.2 You must not do anything, or allow someone else to do anything, which could put the health or safety of a service user, carer or colleague at unacceptable risk.
* 9 Be honest.
  + Personal and professional behaviour.
    - 9.1 You must make sure that your conduct justifies the public’s trust and confidence in you and your profession.
* 10 Keep records of your work.
  + Keep accurate records
    - You must keep full, clear, and accurate records for everyone you care for, treat, or provide other services to.

**MISCELLANEOUS**

[**PHSO: Use of Audio and Video Recordings as Evidence**](#_top)

* What is the law on the secret recording, videotaping (or photographing) of individuals?
  + There is no actionable law of privacy in the UK and nothing in English (or Scottish) law which makes it unlawful for one private individual to record, video record or otherwise film another without consent, unless it is for the purposes of “voyeurism” under the Sexual Offences Act 2003.
* Can PHSO use secretly recorded information?
  + There is also nothing in law to prevent us using secret video recordings.

**EPILEPSY RESEARCH AND STATISTICS**

[**Epilepsy Statistics**](#_top)

* House of Commons Library – SN/SG/5691 (2010)
  + 402,000 registered with GP as having epilepsy
  + 20-30% misdiagnosis rate (non-epileptic conditions incorrectly diagnosed as epilepsy - NICE)
  + 80% of GP registered sufferers recorded as seizure free for at least 12 months
* Public Health England – National Neurology Intelligence Network
  + 3,291 deaths in 2014 due to epilepsy in people aged 20+

**EPILEPSY RESEARCH AND STATISTICS**

[**Medscape: Sudden Unexpected Death in Epilepsy**](#_top)

* 1-2% annual risk of SUDEP with primary generalised epilepsy when epilepsy history longer than 30 years.
* SUDEP accounts for 8-17% of deaths in people with epilepsy.
  + In a few witnessed cases, the immediate event before death was respiratory arrest (obstructive and central).
  + Most victims victims were reported were reported to have had difficulty breathing before death.
  + Respiratory events, including airway obstruction, central apnoea, and neurogenic pulmonary edema, are probable terminal events.
* SUDEP risk factors:
  + Prone position.
  + Unsupervised after seizures.
  + Symptomatic seizures.
  + Tonic-clonic seizures.
  + Younger age of seizure onset.
  + Duration of seizure disorder.
  + Higher number of seizures.
  + Recent seizures.
  + Nocturnal seizures.
  + Higher number of anti-epileptic medications.
* Epilepsy-related causes of death account for 40% of mortality in persons with epilepsy and include the following:
  + Death due to the underlying neurologic disorder in symptomatic epilepsy.
  + Sudden unexpected death in epilepsy (SUDEP).
  + Accidents during epileptic attack (i.e. trauma, drowning, burning, choking).
  + Status epilepticus.
  + Suicide.
  + Treatment related death.
* SUDEP Deterrence and Prevention:
  + Medication.
  + Surgery.
  + Close monitoring of the patient during and in the minutes and hours after a seizure can be life-saving.
  + Caregivers need to be trained in the acute management of tonic-clonic seizures, including in the positioning of patients during and after the attack and in the delivery of cardiopulmonary resuscitation.
  + Respiration needs to be monitored during the post-ictal period. Stimulating patients post-ictally is believed to reduce the chances of apnoea.
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**EPILEPSY RESEARCH AND STATISTICS**

[**Sudden Unexpected Death in Epilepsy: A Series of Witnessed Deaths**](#_top)

* To conclude, in this series, the largest collection of sudden deaths to date, only 11% of deaths were witnessed and most of these occurred in association with a seizure [twelve with GTCS, two with post-ictal and one with aura].
* The account of these deaths support the view that both central and obstructive apnoea play important parts in the genesis of SUDEP, with most witnesses stating that the victims experienced breathing difficulties.
* Airway obstruction seemed to be a significant factor in at least two cases and it is therefore possible that deaths presently categorised as SUDEP occur through various mechanisms.
* Although resuscitation was unsuccessful in the cases described most sudden deaths remain unwitnessed.
* One possible explanation for this is that where seizures are witnessed and recovery is monitored timely assistance by positioning of the patient or stimulation of respiration may prevent a fatal outcome in some cases.
* This raises the important issue of supervision.
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**EPILEPSY RESEARCH AND STATISTICS**

[**SUDEP Action: Risk Avoidance and Supervision**](#_top)

* Broadly speaking, SUDEP either occurs because seizure activity affects the heart (both directly and via release of hormones) causing a dangerous change in heart rhythm during or just after a clinical seizure, **or because the respiratory centre in the brain stops working during a seizure and does not spontaneously recover.** It is of course possible that there may be other mechanisms, but the vast majority of cases seem to fall into one of the above categories. Stopping seizures occurring by effective treatment and management of the epilepsy would therefore prevent most instances.
* As more is understood about the genetics of abnormal rhythms in heart and brain, the possibility emerges of identifying those at risk of such abnormal rhythms by specialized tests and using more targeted medication. Meanwhile, first aid might include staying with the person for a while after the seizure has apparently abated.
* **Where seizures still occur despite the best treatment, it seems that one protective factor is having someone else present who can administer first aid, since we know that SUDEP is often unwitnessed. In some people, seizure-related respiratory arrest is associated with EEG flatlining, with recovery occurring if the person is attended. Being rolled to the recovery position may be associated with breathing restarting and therefore may prevent this type of SUDEP, as the brain is stimulated by the passive muscle movement.**
* **In both cases, breathing-related and heart-related, the issues of monitoring and of accompaniment arise.**
* In our community-based epilepsy service in Cornwall UK we have only had one case of SUDEP in 14 years, although on epidemiological grounds we should have had 30-60 given the size of our clinical population and severity of their epilepsy.