Independent Review Panel for NHS Continuing Healthcare

Ms Agnes [redacted]

Meeting held on 28 August 2013 at 1.0pm

Case Reference No: [redacted]
Remit of Panel

The Independent Review Panel (IRP) NHS England - Midlands and East is a statutory body required by the Department of Health to independently consider the process followed by NHS agencies within the region with regard to decisions they have made on a person's eligibility for NHS continuing healthcare funding and, when doing so, it follows guidance issued by the Department of Health which apply to the NHS England and every Clinical Commissioning Group (CCG), Commissioning Support Unit (CSU) and social services authority in England.

NHS England's Review Procedure

NHS England's independent review process is in place so that NHS service users can request a review of the outcome of their assessment of eligibility for continuing healthcare funding and that decisions reached by NHS agencies in the Midlands and East region are duly and independently considered.

IRP Terms of Reference

The IRP can consider cases in the following circumstances:-

- when NHS service users are dissatisfied with the procedures followed by an NHS agency when assessing their eligibility for continuing healthcare funding;
- when its service users do not agree with the way in which the "primary health need test", as set out in the National Framework, has been applied by NHS agencies in Midlands and East region;
- when local dispute resolution procedures concerning a decision by NHS agencies in Midlands and East region have been followed and this has not resolved matters.
- when NHS England - Midlands and East office is satisfied that requiring a person to follow local dispute resolution would be unreasonable and cause undue delay

1 INTRODUCTION

This document is a summary record of the IRP convened to consider a claim for NHS fully funded continuing healthcare in relation to Ms Agnes [redacted]. For the purposes of brevity and clarity the title PCT is used throughout the report as this was the agency making the assessment.

2 SUMMARY OF INTRODUCTORY REMARKS BY THE CHAIR OF THE IRP

The Panel Chair welcomed Mr and Mrs [redacted], Ms [redacted] and Ms [redacted]r and introduced them to the members of the Panel. He explained the role of the Panel and that the decisions available to it were;

a) to uphold an appeal,

b) to reject an appeal

c) to refer a case back to the assessing agency for further consideration

He also explained to the family that whatever decision the Panel reached on their appeal that they could still continue to appeal via the NHS Ombudsman and that NHS England would follow cooperate with this process.

The Panel Chair went on to explain that NHS England and its IRP welcomed the attendance of those making appeals because it provided opportunity to better understand what had transpired when someone had been assessed for eligibility for continuing healthcare funding. He also explained that there may be a need to ask questions they may find distressing but that this was necessary if the Panel was to fully understand Ms [redacted]' care needs.

The Panel Chair confirmed the period of appeal with the family and CCG and it was noted to be 4 September 1998 to 6 November 2002. The Panel Chair confirmed that the Norfolk, Suffolk and Cambridgeshire SHA criteria would be used to consider the case as these were the criteria in place during this period and Mr [redacted] raised concern about the previous SHA criteria.

The Panel Chair explained that in 2003 all Strategic Health Authorities had to confirm that their criteria were Coughlan compliant and the Independent Review Panel worked on the basis that the criteria were compliant. He explained that the Ombudsman had requested confirmation that criteria were legally compliant and requested that Strategic Health Authorities make arrangements to retrospectively review all cases where a person may have been eligible against the criteria in place at that time. The National Framework had not come into force until 1 October 2007 and could not be applied to cases prior to this. The Panel Chair explained, however, that the Independent Review Panel would not only look at the Norfolk, Suffolk and Cambridgeshire SHA criteria but would also use the Decision Support Tool (DST) in the National Framework to ensure that all Ms [redacted]' needs had been fully considered.

Mr [redacted] explained that he felt the National Framework was fairer and looked at the levels of need rather than the yes/no tick box of the old criteria. The previous SHA criteria appeared to be set very high and made it difficult for a person to meet the criteria where the National Framework allowed for a discussion about the overall levels of need. The Panel Chair also explained that should the family wish to challenge the legality of the criteria that had been applied that this was a matter for the courts and not the Independent Review Panel.

3 BACKGROUND

Ms [redacted] was admitted to Hospital on 23 May 1998 with confusion and disorientation. On admission she was also found to be suffering from bowel cancer which was successfully operated upon. Ms [redacted] was moved to Hartismere Hospital in August 1998 for a period of rehabilitation before being admitted to [redacted] Residential Home on 4 September 1998.

4 FAMILY PRESENTATION

Mr and Mrs [redacted] presented their case to the Panel and explained that they would be focussing on their submission dated 16 August 2013 (copies of which had already been made available to the Panel and the PCT). Mr [redacted] informed the Panel that the cancellation of the original Panel in July had given him the opportunity to relook at the case and provide an updated submission. He had also provided his own version of the Decision Support Tool which was based on what he believed was a thorough review of the documentation provided to him. He also informed the Panel that in his view the review completed by the PCT had some errors in it, particularly in terms of the completion of the primary health needs test, and he had highlighted these in Appendix B of his submission.

Mr [redacted] talked through what he believed the PCT's errors in detail. He explained that in the primary health needs test the PCT had stated, in the second paragraph, that Ms [redacted] was able to weight bear which was not the case and she had been unable to weight bear since her admission to the home. It also stated that 'she was able to transfer with support from two carers and a handling belt but Mr [redacted] believed as actual fact that Ms [redacted] required a hoist rather than a handling belt and often three carers had been required as it was painful for her to be moved due to severe arthritis and this process was scary and difficult for her. There was also mention, in the nature section of the primary health needs test, that there was no evidence to suggest Ms [redacted] was at risk of choking but the family had identified that there were 18 choking incidences recorded in the care home notes. She was at risk of choking and tended to stuff too much food into her mouth and would not swallow properly requiring the care staff to inspect her mouth and check that no food was present. This had led to her vomiting at times and there were various references to this in 1999 and 2000. The PCT had also indicated that Ms [redacted]' skin was intact but this was also incorrect as she suffered from instances of skin blistering. A GP had indicated that she was at severe risk of bed sores and required application of cream on a daily basis to prevent skin blistering.

Mr [redacted] informed the Panel that the PCT had indicated that Ms [redacted]' needs were not intense, lengthy or frequent. A GP from Ms [redacted]' surgery had contacted the family in 2002 as it became clear at this time that her needs were too great for the care home and there was an attempt to move Ms [redacted] to a nursing home at that time. The daily care records indicated what her daily routine and care plans were and over a 24 hour basis the carers had spent between 7.3 and 8.5 hours with Ms [redacted]. The family felt her needs were intense and that she required a lot of care. The records indicated there was a need to monitor her constipation and administer laxatives. This had been a particular issue in 2002 when cocodamol was required on a daily basis as Ms [redacted] was severely constipated and suffered pain, from December 2001 to October 2002 Ms [redacted] had 670 doses of Lactulose, 340 doses of isphagula and 300 doses of Senna. In 1999 Ms [redacted] had required 15 district nurse visits and 12 enemas had been administered. Mr [redacted] informed the Panel that the actual figures were likely to be higher as not all the daily care records were available.

The Panel noted Mr [redacted]' comments about his mother's needs being intense and asked if this was the same for the whole appeal period. The Panel also noted that at the time the discussions took place about Ms [redacted] being moved to a nursing home, correspondence indicated that the family felt her needs were primarily for personal and social care.

Mr [redacted] explained that he felt his mother's needs were intense for the whole period from 1998 onwards. Mr [redacted] also explained that at the time of his mother's suggested move to a nursing home, he had not been aware of what his mother's needs actually were as the family were not kept informed of what was going on. It was also the case that the frequency and timing of the family visits did not allow for a clear picture of Ms [redacted]' care needs to be obtained. However, having now had access to and read the care home records the family felt very differently about Ms [redacted]' needs. Prior to her admission to hospital she had been quite mobile and, apart from some memory issues, was fairly able to look after herself with input from carers. It was just prior to her hospital admission that Ms [redacted] had been found wandering in the road and she had deteriorated from this point. There had been discussions about her going into [redacted] Care Home prior to this and on discharge from hospital she was moved to the home without any real discussion about whether this would meet her needs and the family questioned this at the time.

5 PCT PRESENTATION

Ms [redacted] and Ms [redacted] presented the case on behalf of the former Suffolk PCT.

Ms [redacted] explained that she had retired from the PCT in 2010 and had been subsequently asked to provide support to the continuing healthcare team in 2011 to work on retrospective reviews this one being one of her early cases. She explained that the case was passed to her in May/June 2011 and her first action was to access the records and collate the case file. A needs portrayal was developed and information back to 1996 was included to highlight the diagnosis of dementia and the point at which the mental health team withdrew. The needs portrayal had been sent to the family and Ms [redacted]

explained that she met with the family in May 2012 to discuss other information that may be available. She had also explained that the case would need to go to the PCT's local panel and the family would have the opportunity to attend. Ms [redacted] informed the Panel that she had presented the case to the local PCT panel but had not contributed to, or taken part in, the actual decision making. She did, however, remain present when the decision was being made.

Mr [redacted] informed the Panel that while the family had been sent the needs portrayal and some other documentation, not everything had been provided at that time. The family confirmed, however, that they had now been party to the full case file.

The Panel Chair noted Ms [redacted]'s role at the local panel and explained that in the spirit of openness and transparency, when using an external assessor it would be appropriate for the PCT to treat them the same as the appellants and ask them to leave at the same time and the PCT took note of this. The Panel also noted that there was a suggestion in the file that in 1998 there had been some debate about whether joint funding would be appropriate and there was also a social services review about Ms [redacted]' placement in 2002 which it was not clear the PCT had been involved in.

Ms [redacted] explained that a summary of the PCT's involvement in Ms [redacted]' case was included within the case file. It was clear that Ms [redacted] was admitted to an elderly mentally infirm (EMI) unit in [redacted] in 1998 and there was various correspondence about whether she should be moved to a nursing home. The care home had been managed by Suffolk County Council until 2002 when a review of care home provision was undertaken by the Council and patients were reviewed to ensure that they were appropriately placed. The PCT had little awareness of Ms [redacted] apart from input from the GP and District Nurse and the review in 2002 had been conducted by social services without input from the PCT. While the care records provided were quite comprehensive, it was noted that some records were missing. However, the records provided did indicate the degree of support Ms [redacted] required and also indicated a short time when Ms [redacted] was moved to a different care home due to [redacted] being refurbished.

The Panel asked when the PCT first became aware of Ms [redacted] and the Presenting Officers explained that this was in 2004 once the family had requested a retrospective assessment for continuing healthcare funding. Due to some administration errors the case had not been moved forward until the family came back to the PCT in 2009 with work not actually starting until the case was passed to Ms [redacted] in 2011. There was no indication that any assessments had been completed previously and the family agreed that they were not aware of any but understood that an assessment for continuing healthcare should have been carried out on discharge from hospital.

The NHS England representative informed the Panel that despite the close down of pre 2004 cases in 2007, it had been agreed that Suffolk PCT should proceed with Ms [redacted] case due to the claim having initially been put forward in 2004. The PCT also acknowledged that there had been administrative and procedural errors that had led to unwarranted delays.

6 DISCUSSION AND QUESTIONS ARISING

The Panel noted that Ms [redacted] had suffered with cancer of the large bowel which was surgically removed without the need for a colostomy. The family explained that this was the case and they also explained that they were not aware that the cancer had spread although they had been told very little by the hospital. The family were not aware of any radiotherapy or chemotherapy having taken place.

The Panel also noted that, prior to and during her hospital admission, antipsychotic medication (trifluoperazine and risperidone) had been prescribed to help with the agitation associated with Ms [redacted]' dementia. The Panel asked if there had been any side effects of these medications. The family explained that they were aware that there was concern about some of her medication but were not aware of the actual issues and Ms [redacted]' GP appeared to be managing this. The family felt the medication may have been causing hallucinations when she was in her own home as she had talked about her granddaughter staying with her, which was not the case. The Clinical Advisor explained that one of the potential side effects was for the patient to develop a tremor and the family explained that they did remember Ms [redacted] suffering with a tremor. The medication had eventually been stopped about the time Ms [redacted] moved to the care home but it was thought Ms [redacted] continued to suffer hallucinations. The Panel noted the advice from the mental health team for the care home staff to try heminevrin as a night sedative if needed. The care staff had been left to choose when to give this medication as a night sedative, which implied quite a responsibility for staff who had no nursing training. The care home records, however, did not show that the drug had ever been administered.

The Panel noted that Ms [redacted]' skin tended to blister and asked the family if the cause of this had ever been discussed with the family. Mr [redacted] explained that his mother was incontinent and he assumed that issues with her skin were caused by this. She did have a tendency to scratch her legs and often appeared to be itchy requiring Piriton to reduce the itching. The family explained that they were not informed about whether the blistering was just on the areas that came into contact with urine or whether the blistering extended to other areas.

Mr [redacted] informed the Panel that his mother had been gradually deteriorating over a two year period. She had been on pain relief, Piriton for her itching and senna and lactulose for her bowels. Just prior to her death the hospice nurse had visited and, with the agreement of the GP, morphine was commenced. Mr [redacted] explained that the family had not been consulted about this at the time. Ms [redacted] had been fairly stable for the ten months previously but there appeared to be a sudden change in her condition. She became more uncomfortable in bed and the risk of pressure sores increased and there were also difficulties in moving her. The Panel noted that the records indicated a general deterioration in Ms [redacted] condition in 2002 and Ms [redacted] was spending more time in bed, with two hourly turning being carried out by care staff. The palliative care team were called in October and this was the point that morphine was prescribed with a syringe driver being put in place on 30 October 2002.

The Panel noted that the records did not indicate any input from dieticians. The Presenting Officer explained that staff monitored Ms [redacted]' weight and also monitored

her intake as she tended to put too much food in her mouth and would forget to swallow. She was increasingly fed by the care staff and her weight appeared stable apart from the last few months when she was reluctant to take food and fluids and there was some weight loss recorded. The family indicated that they had noted some weight loss and remembered a time when her flesh appeared to hang from her arms. Her diet was variable and at times she ate well but at other times she needed a lot of encouragement.

The Panel noted that Ms [redacted] was prone to choking and asked the family more about this. Mr [redacted] explained that there had been 18 recorded incidences of choking between 1998 and 2001. The Presenting Officer explained that the review in December 1998 indicated that Ms [redacted] had a good appetite but required a soft diet to try and prevent choking.

The Panel noted that Ms [redacted] was diagnosed with dementia in 1996 and had been seen by the mental health team until her admission to the care home in 1998. The Panel noted that there was nothing in the file to indicate that Ms [redacted] suffered with any other psychiatric problems such as depression and the family confirmed that they were not aware of any.

Mr [redacted] informed the Panel that, during her stay in the home, his mother did not really appear to know who her family were but always appeared to be happy to see visitors even if she had no understanding of who they were. She was unable to engage in any meaningful conversation and her verbal communication did not make any sense. While she was able to use some words, she could not construct meaningful sentences. Ms [redacted] was unable to understand risks and would have tried to drink hot tea if the care staff did not manage this for her. Mr [redacted] explained that he was not aware if his mother was able to make any choices about food but would push it away if she did not want it. Her eyesight was poor and she required glasses but did not often wear these. The Panel asked if Ms [redacted]' hallucinations appeared to cause her any distress. The family explained that there were occasions when they knew that something was upsetting her and she might cry at times.

The Panel asked what Ms [redacted] would do during the day. Mr [redacted] explained that the care staff would put her in her wheelchair and moved her to the lounge and she would stay there for most of the day. Occasionally carers would take her into the garden or out on trips but this had stopped by the time of the appeal period. The family thought the carers would try to include her in everything that went on in the home and were always very nice and caring towards her.

The Panel asked if the family had been involved in Ms [redacted]' move to [redacted]. The family explained that she was already on the list to go to [redacted] so when leaving hospital she was automatically admitted there. Mr [redacted] explained that he had questioned whether his mother required a different placement as he was not sure that the home would be able to cope with her needs.

The Panel noted Suffolk PCT's application of the Norfolk, Suffolk and Cambridgeshire SHA criteria and asked the family what they felt about the comments made by the PCT Panel. The family explained that they felt the comments were reasonable but did not agree with

the decision. The Panel noted that criteria five, within the Physical and Sensory criteria, indicated that in certain circumstances a person could be eligible for continuing healthcare if they did not meet the other four criteria but where the multi disciplinary team agreed that they had an overwhelming health need. The PCT had indicated that this was not applicable but the Panel asked whether Ms [redacted] overall healthcare needs had been considered. Ms [redacted] explained that she was unsure and was, therefore, unable to comment on this.

The Panel Chair noted that within the application of the primary health needs test the PCT Panel had indicated that Ms [redacted] was dependent on the carers for all her needs and there was some interaction between her cognition and communication. The PCT Panel then went on to say that Ms [redacted]' needs were not complex on their own but when combined there was a level of complexity due to interrelation in her needs. Ms [redacted] explained that the local review panel felt that there was some interaction but that, overall, Ms [redacted]' needs were not complex. The Panel noted that the PCT panel had agreed that there was some intensity around Ms [redacted]' personal and social care needs and Ms [redacted] explained that it could take some time to carry out interventions around washing, dressing and feeding. Mr [redacted] explained that her continence needs could also be intense with the requirement for two hourly turns. Ms [redacted] acknowledged that the wording used in the application of the primary health needs test was confusing and changes had now been made to the way the discussion around the four areas was recorded.

The Panel noted the Decision Support Tool provided by the family which set out their views on Ms [redacted]' needs and highlighted the areas where they disagreed with the PCT including cognition, mobility, communication, continence and drug therapies. Mr [redacted] explained that he felt his mother's cognition was severe. Prior to her admission to hospital she was struggling to remember things and this, and her behaviour, had become more of a concern following her move to [redacted]. She struggled to recognise her family and was unable to make choices or assess risk. The Panel noted that Ms [redacted] would not like to talk about her feelings and the family were not aware if she cried or got upset when they left after a visit. Ms [redacted] was unable to weight bear and because of this was at risk of falls and required a lap strap when in her wheelchair. The carers would attempt to get her up most days but at times she was very sleepy and would not want to leave her bed.

The Panel Chair noted that there was mention about Ms [redacted] being moved to a nursing home and correspondence about guardianship under the Mental Health Act or use of the National Assistance Act in order to achieve this. Mr [redacted] explained that Suffolk County Council had been discussing this possibility and at the time the family had not really understood why, although this was clearer now. However this was dropped in the end. Ms [redacted] explained that there had been a deterioration in Ms [redacted]' physical needs and it had been suggested that she may require a different placement. The Panel also noted that the summary provided by the PCT indicated that there was discussion about joint funding in October 2002. Ms [redacted] explained that this did not appear to have been taken forward at the time.

7

In checking the procedure followed by an NHS agency, the IRP focuses on several aspects of the **PANEL'S TERMS OF REFERENCE (TOR) AND FINDINGS**

TOR1: To look at the procedure followed by a PCT or an NHS Trust in reaching a decision about a person's need for continuing health care.

process which are scrutinised by the Health Service Ombudsman should a complaint about an assessment for NHS continuing healthcare funding be received by that organisation.

These are:

- gathering and scrutiny of contemporaneous clinical information /
- involvement of the patient and/or their representative in the assessment process or development of needs portrayal
- decision by a local review panel
- detailed decision letter clearly linked to the primary health need test
- overall quality of assessment documentation.

The Panel's findings in each of these areas are discussed below.

7.1 Contemporaneous clinical information

In terms of the review undertaken by the former Suffolk PCT, the Panel was satisfied with the content and level of detail taken into account.

The local review panel considered the following documents:

- Case Summary
- Care Needs Portrayal
- Continuing Healthcare Assessment
- Social Services Records
- Mental Health Records
- Risk Assessments
- Care Home Records
- Correspondence to and from the PCT and family

In addition to the materials listed above, the Independent Review Panel considered the following documents:

- An SHA review questionnaire completed by Mr [redacted]
- Minutes of the local review panel
- The decision/rationale letter provided by the PCT

The Panel also had the benefit of verbal contributions from Mr and Mrs [redacted], Ms [redacted] and Ms [redacted] on behalf of the former Suffolk PCT.

7.2 Involvement of the patient and/or representative

The Independent Review Panel was satisfied that the PCT had made efforts to involve the family.

7.3 Local review panel

The local review panel was multi-disciplinary in composition.

7.4 PCT decision letter

The decision letter and accompanying documentation provided by the PCT was considered to be satisfactory and aimed to provide a rationale for the decision reached. However, the Panel noted that the completion, discussion and recording of the primary health needs test was confusing at times.

7.5 Overall quality of assessment process

The Independent Review Panel was satisfied with the overall quality of the assessment process. An assessment of need had been carried out which was evidenced by supporting documentation. The family had been given the opportunity to contribute to the assessment. However, as previously mentioned there had been administrative and procedural errors causing unwarranted delays.

TOR 2: To examine the primary health need decision by a PCT

In order to make recommendations regarding the primary health need, the Panel undertakes two procedures:

- domain-by-domain discussion of the care needs assessment using the Decision Support Tool as set out in the National Framework For Continuing Healthcare and NHS-funded Nursing Care;
- an evaluation of a person's care needs against each of the key indicators (nature, intensity, complexity and unpredictability) associated with establishing whether a person has a primary health need.

7.6 Discussion of assessment domains

The Panel used the Norfolk, Suffolk and Cambridgeshire SHA criteria, this being the policy and procedural guidelines in place during the appeal period. The Panel also agreed to use the Decision Support Tool from the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (2007) in order to ensure they had fully considered Ms [redacted]' care needs.

The Decision Support Tool assists NHS and social care professionals when assessing a person's care needs and when determining if they meet the eligibility for NHS continuing

healthcare funding. The tool is split into twelve care domains, each of which is divided into a number of levels, to which a weighting is given.

The Panel looked in detail at Ms [redacted]' needs and considered the appropriate weightings such needs taking into account the views of the family and PCT.

A copy of the assessment of the care domains is attached.

7.7 Four key indicators

The National Framework for NHS Continuing Healthcare Funding and NHS - funded Nursing Care sets out four key indicators, namely, nature, intensity, complexity and unpredictability to be considered when establishing whether a person has a primary health need and is, therefore, eligible for continuing health care funding.

The Panel considered the way in which the key indicators interacted with each other and made the following observations.

7.7.1 Nature

Nature refers to the type of needs, and the overall effect of those needs on the individual, including the type ("quality") of interventions required to manage them.

The Panel noted the type and level of Ms [redacted]' needs as identified by the Decision Support Tool. Ms [redacted] was noted to be anxious and restless and suffered some episodes of challenging behaviour including taking food from other residents and removing her lap strap. There was no indication of any physical aggression and Ms [redacted] did not appear to be resistive to care interventions. Her behaviour potentially put her at risk of falls at times but this could be managed by the care staff and her episodes of challenging behaviour reduced in frequency during the appeal period. The Panel could find no indication that Ms [redacted]' behaviour posed a severe risk to herself or others requiring a skilled response to reduce this risk. Ms [redacted] was severely cognitively impaired and was confused and disorientated to time, place and person. She had poor short and long term memory and struggled to make choices or assess risk. Due to her poor cognition, Ms [redacted] struggled to understand and communicate her needs and her verbal communication was noted to be confused and muddled. She relied on care staff to anticipate her needs through familiarity with her and also using non verbal signs of communication. Ms [redacted]' eyesight was poor and she did not wear her glasses most of the time. Ms [redacted] suffered some episodes of anxiety and distress and could have episodes of tearfulness. She had a previous history of hallucinations which it was felt would have upset her at times. Ms [redacted] appeared to respond to routine reassurance and there was no indication that it was difficult to calm her. Ms [redacted] struggled to engage in care planning and activities due to her poor cognition rather than her actively withdrawing due to being depressed.

Ms [redacted] was bed or chair bound and required a hoist and two carers, or occasionally three, for transfers. She was assessed as being at medium risk of falls but due to Ms [redacted] fiddling with her lap strap, the risk of falls increased and the Panel noted that Ms

[redacted] suffered falls during this period. Ms [redacted] suffered with flexion deformity of her knees making it difficult for her to straighten her legs and this could make certain positions uncomfortable for her. Due to this, care staff had to be careful when moving her and had to be aware of the potential for her to suffer pain if not correctly positioned. The Panel could not find any indication that Ms [redacted] suffered a clinical condition that had made it impossible to move her in any way or where positioning was critical as might have been the case with the need to maintain a clear airway. Ms [redacted] required assistance with eating and increasingly required feeding. She had a tendency to put too much food in her mouth and needed prompting to swallow. This put her at risk of choking and vomiting and there had been a number of incidences during this period. However, there was no indication that Ms [redacted] required suctioning due to episodes of choking or aspiration. Ms [redacted] suffered some weight loss near the end of the period and required supplements but there was nothing to indicate that she was nutritionally at risk. Ms [redacted] was doubly incontinent and prone to constipation requiring enemas. There was no indication of frequent urinary infections and while district nurses had been required to give the enemas, it was not felt that her continence regime was problematic requiring a high level of skill as might have been the case with, for example, the need for bladder washouts. Ms [redacted] was at high risk of pressure damage and while she did not suffer any pressure ulcers, her skin was often irritated and itchy and she was prone to blistering. She required monitoring of her skin, application of cream to reduce the risk of breakdown and oral piriton to reduce itching. There was no indication of the need for specialist wound dressings.

Ms [redacted] was non-concordant with her drug regime, due to her poor cognition, and required administration of her medication. Her drug regime was felt to be routine and there was no indication that she required regular review or change to her drug regime due to her condition fluctuating. Ms [redacted] had been on antipsychotic medication in the past which required a level of skill and judgement on when to administer but this appeared to have been stopped about the time of her admission to the care home. Ms [redacted] suffered some pain and was on effervescent Co-Codamol 8/500 medication to assist with this but, due to her poor cognition and communication, she relied on the carers to monitor her for signs of pain and to also look for potential changes in her condition caused by side effect of her medication. Ms [redacted] did not appear to suffer any seizures or altered states of consciousness and there was no indication of any ongoing shortness of breath.

The Panel agreed that Ms [redacted] had a range of needs and, due to her poor cognition and communication, required assistance with all activities of daily living. There had been a gradual deterioration in Ms [redacted]' cognition during the appeal period but the major deterioration in her condition was prior to her admission to the care home and had been, in part, caused by her hospitalisation and surgery. The hospitalisation had also led to her becoming more frail. The Panel agreed that, overall, they felt the predominance of Ms [redacted]' needs were for personal and social care. The interventions required to meet her needs were not felt to be particularly complex and there was no indication that a high level of skill or knowledge was required.

7.7.2 Intensity

Intensity describes both the extent ("quantity") and severity (degree) of the needs, including the need for sustained care ("continuity"). The Panel also considers whether a combination of seemingly low-level needs may combine to create intensity.

The Panel noted that, due to Ms [redacted]' poor cognition and communication, she required assistance with all activities of daily living and also required carers to spend time with her ensuring correct interpretation of any non-verbal signs of communication. Ms [redacted] had periods of anxiety and restlessness which had led to some incidences of challenging behaviour but these did not appear to be particularly frequent in nature and actually reduced in frequency during the appeal period. Ms [redacted]' behaviour was not felt to be severe or problematic to manage requiring lengthy interventions but a level of monitoring was required to protect her from harm. Ms [redacted] also suffered episodes of distress and anxiety but appeared to respond to routine reassurance and there was no indication that lengthy interventions had been required to calm her or manage disturbance in her mood.

Ms [redacted] was bed or chair bound and required hoisting for all transfers. Due to the flexion deformity of her knees she required careful positioning when being moved and this may have increased the time that it took for transfers. There was also an indication that three carers were required at times. However, overall the Panel did not feel that transfers were intense. Ms [redacted] was at risk of falls and her tendency to fiddle with the lap strap on her wheelchair meant that care staff needed to monitor her to prevent falls but this was not felt to be particularly intense. Ms [redacted] required assistance and prompting with feeding and her tendency to put too much food in her mouth requiring carers to monitor her for signs of choking or vomiting. Due to this it could take her a long time to finish a meal and this could make her nutritional needs intense at times. The Panel noted that there had also been some weight loss near the end of the period and care staff were required to monitor her intake more closely. Ms [redacted] was doubly incontinent and prone to constipation requiring input from the care staff to manage this but the Panel did not feel her continence needs were particularly intense even though enemas had been required at times. Ms [redacted]' skin needs were also not felt to be intense and, although monitoring of her skin was required to look for signs of pressure damage and blistering and the application of cream was required, her skin had remained relatively intact. Ms [redacted] required administration of her medication due to non-concordance and relied on care staff to monitor her for potential side effects of her drug regime and signs of pain. It was not felt that the level of monitoring was particularly high and there was no indication of the need to return frequently to administer medication due to non-compliance.

The Panel agreed that there was some intensity around Ms [redacted]' personal and social care needs due to the need to assist her with all daily activities, interpret her limited communication and feed her. However, the Panel could not identify elements of intensity with regard to her health care needs. The level of her needs was not felt to be particularly severe and her needs were not felt to be particularly problematic to meet. Ms [redacted] had not required frequent or lengthy interventions to meet her health needs and, overall, the number of care staff required was not high. The Panel noted, however, that at times three staff were required to assist with transfers but this did not appear to be particularly frequent. The Panel noted that Ms [redacted] had a range of needs, but there was no

indication of the need for almost constant interventions over a 24 hour period to meet her needs.

7.7.3 Complexity

Complexity refers to how the needs arise and interact to increase the skill needed to monitor and manage the care.

The Panel noted that while Ms [redacted]' poor cognition and communication required care staff to spend time with her ensuring correct interpretation of her needs and wishes, there was nothing to indicate that this had made her needs significantly harder to meet. Ms [redacted] showed some challenging behaviour but there was no indication that her behaviour had posed a barrier to care being delivered. While her tendency to remove her lap strap potentially increased her risk of falls, routine monitoring helped to reduce this risk and her behaviour did not appear to pose a serious risk to herself or others requiring skilled intervention as might have been the case with physically aggressive or threatening behaviour towards others. Ms [redacted] suffered some anxiety and distress but she appeared to respond to routine reassurance and there was no indication of the need for skilled intervention or the use of medication to calm her down.

Ms [redacted] required monitoring to help reduce the risk of falls and while her care staff required some understanding of the potential causes of her falls, the level of skill required when monitoring her was not regarded as high. The Panel agreed, however, that due to the flexion deformity of her knees, a level of skill and knowledge was required when moving her and she required carers to carefully position her and to be aware that some positions were uncomfortable for her. Despite this, care staff continued to be able to move her and there was no indication that it was impossible to move her or that a very high level of skill had been required. Ms [redacted] was doubly incontinent and prone to constipation and a level of skill was required to administer enemas during this period. Apart from this, her continence needs were not felt to be complex and there appeared to be no significant issues arising from her previous diagnosis of cancer of the bowel and her treatment for same. Ms [redacted]' poor mobility and double incontinence put Ms [redacted] at high risk of pressure damage and while her pressure areas remained intact, her skin was prone to blistering and irritation requiring monitoring and the application of creams. The Panel could find no indication that a high level of skill was required around her skin as might have been the case with the need for specialist dressings or to manage pressure ulcers extending to underlying bone. Ms [redacted] required prompting and assistance with feeding and her tendency to put too much food in her mouth put her at risk of choking. Due to this care staff needed to closely monitor her when eating and a level of understanding of the risks associated with this was required. However, there was no indication that any episodes of choking or aspiration had occurred which had required skilled intervention for suctioning. Ms [redacted] suffered some weight loss near the end of the appeal period but there was no indication of significant weight loss which required skilled intervention from the dietician or other professional to manage this.

Ms [redacted] did not appear to suffer any ongoing breathing difficulties or seizures requiring skilled intervention. Ms [redacted] required administration of her medication and monitoring for potential side effects and pain but this was not felt to be complex with a high level of

skill being required. The Panel noted that Ms [redacted]' inability to verbally communicate required the care staff to ensure that they looked for any non-verbal signs of changes in her condition but this was not felt to require a high level of skill. Ms [redacted]' drug regime was routine in nature and in terms of its administration and she was not on any medication which had required judgement by the care staff on when to give it and in what dose. There was also no indication that Ms [redacted] was on any medication which could only be administered by a nurse or trained carer up to and until the last week of her life when morphine was administered to ease her through her last few days.

The Panel agreed that they did not feel Ms [redacted]' health needs were complex. Her needs were not problematic to meet and there was no indication that a high level of skill or knowledge had been required. The Panel acknowledged that there was some interaction in Ms [redacted]' needs particularly in relation to her inability to communicate changes in her condition, her potential for pain on movement and the increased risk to her skin from her mobility and incontinence. However, the Panel agreed that they did not feel her needs interacted in such a way as to increase the skill and knowledge required to meet her needs. There was also no indication that Ms [redacted] behaviour or psychological state made it more difficult to meet her needs due to her actively withdrawing or episodes of physical aggression.

7.7.4 Unpredictability

Unpredictability refers to the degree to which needs fluctuate, creating difficulty in managing needs; and the level of risk to the person's health if adequate and timely care is not provided. A person may be considered eligible for NHS continuing healthcare funding on the grounds of unpredictability if they have need for monitoring, supervision, or investigations that is not of a nature or extent that a local authority can provide.

The Panel agreed that Ms [redacted]' behaviour appeared to follow a predictable pattern in terms of the type of behaviour she would show although it was not always possible to fully predict when. However, there was no indication of unpredictable and severe outbursts of aggressive behaviour that put herself or others at risk and required prompt and skilled intervention. Ms [redacted] suffered some episodes of anxiety and distress but there was no indication of sudden fluctuations in her mood which did not respond to routine reassurance or required skilled intervention to manage. Ms [redacted]' risk of falls was predictable although it was not possible to tell when she would fall and while she suffered a flexion deformity of her knees, there was no indication of any spasms or movement in the legs that were unpredictable. Ms [redacted]' risk of choking was also predictable and care staff had plans in place to monitor her when eating and there was no indication of the need for prompt and skilled response for suctioning. There was nothing unpredictable about her skin and the Panel did not feel Ms [redacted]' continence needs were unpredictable requiring prompt response as might have been the case with blockages of a catheter. The records did not suggest that Ms [redacted] had required frequent review or change to her drug regime due to her condition being unstable and fluctuating and there was also no indication that she had suffered any severe or unexpected side effects of her drug regime requiring a prompt response.

The Panel agreed that the type and level of Ms [redacted]' needs did not appear to change significantly although there was some gradual deterioration in her condition. Care staff were able to anticipate her needs and there was nothing to suggest her condition was unstable requiring prompt and skilled response. There was also no indication that her care plans required frequent review or change during this period.

8 CONSIDERATION AGAINST THE NORFOLK, SUFFOLK AND CAMBRIDGESHIRE SHA CRITERIA

The Panel considered Ms [redacted]' case against the Norfolk, Suffolk and Cambridgeshire SHA Criteria which was the criteria in place during the appeal period.

People with Dementia

The Panel noted that Ms [redacted] was severely cognitively impaired and struggled to communicate her needs in any way. However, while she showed some episodes of challenging behaviour, there was nothing to indicate that her behaviour had been of a severe or persistent nature requiring psychiatric intervention, continuous assessment or intensive treatment. Ms [redacted] had not shown any violent or aggressive behaviour and there was no indication of disinhibited sexual behaviour, inappropriate defecation or urination or anti-social behaviour. The Panel agreed that while Ms [redacted]' behaviour did pose some risk to herself, there was no indication of the need for input by a skilled mental health professional in relation to this. The Panel could find nothing unpredictable about Ms [redacted]' medical condition and there was nothing to indicate that she had required input from members of the multi disciplinary team due to the risk of deterioration in her physical health and safety.

The Panel agreed that they did not feel Ms [redacted] met the Norfolk, Suffolk and Cambridgeshire SHA People with Dementia criteria for the period 4 September 1998 to 6 November 2002.

Adults with Physical and/or Sensory Disability

The Panel acknowledged that Ms [redacted] had a range of needs during the appeal period but there was no indication that she required extensive healthcare support during a 24 hour period. Her health needs did not appear to be complex and there was nothing to indicate that she had required support over a 24 hour period that could only be delivered by a health professional. Ms [redacted] had not required any specialist health assessment, treatment or management on a weekly basis and there was nothing to indicate her health needs were complex or that her condition was unstable or rapidly deteriorating. Ms [redacted] did not appear to suffer unpredictable or frequent relapses. There also did not appear to have been the need for frequent review or adjustment of her drug regime.

The Panel agreed that they did not feel Ms [redacted] met the Norfolk, Suffolk and Cambridgeshire SHA Adults with Physical and/or Sensory Disability criteria for the period 4 September 1998 to 6 November 2002.

9 RECOMMENDATIONS

Having considered the nature, complexity, intensity and unpredictability of the totality of Ms [redacted]' healthcare needs (taking into account any interaction between those needs and the evidence from risk assessments), the Panel unanimously decided that Ms [redacted]' needs were merely incidental or ancillary to the provision of accommodation and of a nature which it could have been expected that an authority, whose primary responsibility is to provide social services, could have been expected to provide and that consequently Ms [redacted] did not have a primary health need. Therefore the Panel decided that from 4 September 1998 to 6 November 2002, Ms [redacted] was not eligible for 100% funded NHS Continuing Healthcare.

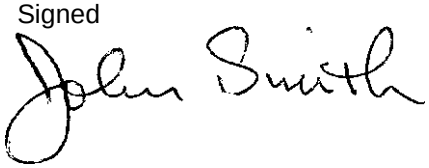
The Panel agreed that while the case was being assessed against the Norfolk, Suffolk and Cambridgeshire SHA Criteria, it may have been appropriate for the PCT to also consider the needs against the Decision Support Tool of the National Framework to ensure that all Ms [redacted]' care needs and the level of those needs were fully considered.

The Panel noted that the PCT's completion of the primary health needs test was confusing in parts and, given that the appellant may wish to exercise the right to refer matters to the Ombudsman, the PCT should give further thought to clarifying their statements under each of the headings, particularly those of complexity and intensity.

10 ADDITIONAL COMMENTS

This report serves as the formal minutes of the Independent Review Panel meeting held on

Signed



John Smith
Chair
NHS England - Midlands and East Independent Review Panel

19/09/2013
28 August 2013 to consider the appeal on behalf of Ms Agnes [redacted]