



Interim Choice Policy for the Provision of NHS Continuing Healthcare Funding / NHS Funded Care for Adults

**A response prepared by Healthwatch Devon to North, East and
West Devon Clinical Commissioning Group**

October 2015

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About this document

This response has been produced by Healthwatch Devon - the independent consumer champion for health and social care in Devon, in line with our remit under s221 of the Local Government and Public Involvement in Health Act 2007.

The document is presented for consideration by Northern, Eastern and Western Devon Clinical Commissioning Group in response to the Commissioning Group's request for feedback in respect of the Interim Choice Policy for the provision of NHS Continuing Healthcare / NHS funded care for adults.

Healthwatch Devon would like to thank those who took the time to share their experiences with us.

Registered Charity Number: 1155202 Healthwatch Devon CIO

Introduction

The role of Healthwatch Devon is to promote and support involvement in the commissioning, provision and scrutiny of services and be the independent consumer champion for Health and Social care in Devon. We obtain the views of local people regarding their needs for, and experiences of local care services and importantly make these views known, by making reports and recommendations about how local care services could or ought to be improved, which we direct to commissioners and providers of care services, and people responsible for managing or scrutinising local care services and shared with Healthwatch England.

We understand that Health and Social Care services are going through a great change and that commissioners and providers must be prepared to offer equitable, safe and effective services, according to need, making the best use of available resources. We must, however ensure that when services change or are redesigned, that this is informed by the views and experiences of those who come into contact with them.

North, East and West Devon Clinical Commissioning Group (NEW Devon CCG) notified Healthwatch Devon of the intention to seek feedback on the interim Choice Policy in June 2015, through the Engagement Gateway process. The interim policy itself was not received until August 2015. On its receipt, we were requested to share the policy and an invitation to stakeholders for comment, through the Healthwatch Devon network of service delivery partner organisations and individual and organisational supporters.

Healthwatch Devon welcomes the opportunity to respond to the request for feedback in respect of the Interim Choice Policy, for the provision of NHS continuing healthcare and NHS funded care for adults. As we were not requested to carry out any specific targeted engagement, our response is based on the experiences that we have captured during the last 12 months, where applications for NHS CHC funding have been made and on the contact we have had with Motor Neurone Disease Association (MNDA).

Specific aspects of the policy for review

The briefing provided by NEW Devon CCG that accompanies the invitation to feedback, lists the four aspects of the policy that they are seeking views on.

1. Distance you travel for care
2. The cost of care packages
3. How meaningful the current name is “Choice Policy”
4. How easy the policy is to understand and which care groups it should cover.

We have taken each of these aspects and addressed them separately below.

Distance travelled for care

We are unable to identify where in the policy travelling distance is made reference to and therefore unsure of the context within which feedback is required.

We are also assuming that this does not refer to the individual receiving care, as the policy states a) in a care home or b) in a person's own home, therefore we are unsure who is being referred to that is required to travel.

Policy aside, we know that timely access to good quality care is an ongoing challenge for people in Devon, as we continue to hear from those who struggle to find the care that they need, when they need it, reporting issues such as staff shortages and an inability to recruit skilled workers; and inconsistencies and lack of communication where several care providers / workers are involved in the delivery of an individual's care package.

We also know that some carers, who have contacted us for advice, have struggled to have their voices heard when trying to arrange nursing care for a loved one. The people that spoke to us said that issues affecting them included: *"the home was close but not on a bus route so I couldn't visit as much as I could if it was a bit further way but on a bus route."*

The cost of care packages

During the consultation period, we were contacted by Motor Neurone Disease Association, (MND) who raised concerns to us in relation to the lack of clarity around the criteria by which people's situations are deemed 'exceptional'. The impact of this can be seen in the case study that is included in their response to this consultation (Appendix 3).

Healthwatch Devon is concerned that this policy, if not amended will result in more individuals being denied their wish to be cared for at home, or in a place of their choice.

The name 'Choice Policy'

We would echo the feedback that has been provided by MND in that the name 'Choice Policy' is not meaningful and does not describe what the policy is for.

The name also suggests that choice is at the fore front of policy aims; however, due to the complexity and wording of the policy, the individual's choice is not paramount and is governed by a number of restrictions, such as budget, resources, timing and assessment.

Where the intentions are described in the policy (1.5) the offer of 'choice' is listed last but one.

Is the policy easy to understand?

We do not consider this policy to be very easy to understand. It is vague, wordy and the language used is not engaging or clear.

It is not easy to find specific information on aspects such as what to do if an individual has a concern, what the criteria is, what the assessment process is, how long this should take etc. which could be listed under clear headings.

In reviewing the policy, we compared it to the [NHS Continuing Healthcare Funding & Funded Nursing Care Policy](#) under which Torbay and Southern Devon Health and Care NHS Trust (TSDHCT) - Now known as Torbay and South Devon NHS Foundation Trust - deliver the NHS Continuing Healthcare service, on behalf of South Devon and Torbay Clinical Commissioning Group. This policy has a simple title, is set out with a contents page and clear introduction. It goes on to describe the criteria and process of assessment, (including references to tools in the appendices) in a constructive way and is easy to follow for both

health professionals and individuals themselves. The information is clearly set for what to do around complaints, safeguarding and responsibility.

In comparison to the TSDHCT policy, we would recommend that NEW Devon CCG considers making the following changes, in order to make their policy clearer and easier to understand.

- 1) Add a contents page
- 2) Change the name of the policy to something more meaningful, that describes simply what the policy covers
- 3) That it describes each aspect of the policy clearly and simply using a set of clear headings, describing a chronological approach where possible.

Which care groups should it cover?

This policy should be accessible to each group that will need access to it -

1. Health and social care professionals
2. Individual care recipients
3. Carers and relatives
4. Support organisations, such as those that are condition specific, or information and advice services
5. It should also be accessible, on request and in a timely manner, to those who need it in an alternative format and the policy should contain details of how to request this.

Other Aspects for Consideration

End of Life Care

Although the experiences that we have captured at Healthwatch Devon set out below do not relate specifically to the implementation of the interim policy in question, they do provide useful insight into how people may be feeling and how they are coping at what can be described as a difficult time, both for the person receiving care and their loved ones, particularly if a person is nearing end of life.

The following accounts / comments shared with us by close family members and carers describe their experiences in relation to the end of life care that was arranged for their loved ones:

Experience 1

“My husband has been receiving palliative care from the Community Home Nursing Team (established by the local Community Hospital League of Friends for the care of older people entering the final stages of life) for just under a year. The Service is managed by NDHT. My husband, due to complex psychological and medical issues, recently had a 2 month stay in residential care. On his return home, I contacted the Home Nursing Team to check when he would next be seen at home. I was told that he was no longer on their list because 'the service is for the palliative care of the terminally ill' - to which my response was 'Yes...? And?'; 'And for those in the last year of life, so your husband will now be seen by the district nurses'. I was speechless. My husband clearly had not had the decency to die within the allocated

time (although his one year is yet to expire - rat her like him, I suppose...). The manner in which this news was imparted was unacceptable; being both utterly callous and also totally without either empathy or insight into the struggles associated with the care of the dying.

District Nurses are valuable and skilled - but they are not skilled in the holistic and specialist care of the complex, terminally ill. We feel bereft that this extraordinarily valuable support and highly specialist nursing service has been withdrawn."

Experience 2

"My mother has been diagnosed with terminal breast cancer and only has weeks left to live. I am struggling to navigate the NHS system to enable her mother to stay at home. I do not want to complain about or criticize the NHS who has been very kind but I feel my mother isn't getting the appropriate care to support her needs.

I am also concerned that mother isn't getting enough nutrients or hydration. I feel my mother's care needs aren't being met. Mother has dementia, issues with incontinence, has huge issues with mobility, needs dressing changed every two days, high risk of infection.

They keep providing my mother with endless pieces of equipment which isn't useful as her health has deteriorated.

I have spoken to several different people and have been told that there's no one in her area that could offer care and I was offered direct payments, but if they can't find care how am I supposed to?

I acknowledged that I am in a very painful place but the whole system is just too difficult when one's emotions are running high."

Experience 3

"I had been waiting for an assessment of my request for NHS Continuing Health Care for my late wife for several years. I had appealed against a decision made not to grant CHC for her, and also to ask for a review for a 6 month period between October 2012 and April 2013 when she had a crisis. The home provided a shedload of information and all I got was a regular letter apologising for the delay due to inadequate staff numbers to deal with the large number of claims.

Last week I received a newsletter from Devon Carers' Voice asking if I would like to give my views on the policy for provision of NHS continuing healthcare (Interim Choice Policy Review). I see from the request that the "Interim Choice Policy" - whatever that means - has operated for 6 months.

My feeling is that they should clear the backlog of previous claims before starting new schemes with fancy names."

Experience 4

“I applied for CNC which eventually received but I found the process very stressful, lack of communication, unable to reach the manager. I would not like to go through this again and I think your methods should be revised.”

Experience 5

“My mother was awarded Continuing Healthcare in May when I received a letter confirming this and that they would fund the home she was waiting to go to.

She has been going to this home for three years for day care and last week a room became available. I thought as I had received the letter to say that they would fund her there would be no problem. However I am now being told that they will only fund her at the Social Services rate of £425 and the home are charging £620. My mother has Alzheimer’s and Vascular Dementia and her needs are complex hence being awarded Continuing Healthcare. The Adult Mental Health Team have spoken to the Continuing Healthcare Team and said that it is important for my mother’s mental health that she continues to attend this home as she would deteriorate if she had to go elsewhere. This home best meets her needs and I cannot understand how they can go back on what they said in May. The situation has been made more difficult because nobody seems to be taking responsibility for sorting this out. The GP said it was the care team, the care team say its continuing care team and in the meantime I did not know where to turn and as a result my own health was suffering.”

Experience 6

A woman told us that she did not have a very good experience with her father's end of life care. He wanted to stay at home but each time help arrived he had a different care worker who did not really know about his condition, or previous care he had received from other care worker. There was a lack of communication between them which made it stressful for both the lady and her father. Nevertheless when her father finally went to a hospice she could not praise it enough.

Experience 7

A person caring for her terminally ill husband wanted him to be able to come home to die. This became possible when she was made aware of the Marie Curie nurses who are able to organise this for families. The carer was really impressed with the work the nurses did and was so grateful that her husband could die at home with his family around him. However, she said that it was pure chance that she heard about the Marie Curie help and that it isn't always possible for families to access this service. She felt that it was really very important for people to know about the service and for everyone who wanted it to be told it was available and be able to access it without difficulty.

Experience 8

We would like you to consider the case study, (Appendix 4) which was included in our recent [Then What? Report](#) of peoples' experiences of leaving hospital. This experience highlights the difficulties faced by families of individuals who are involved in the continuing health care application process.

“The issues are primarily about the inappropriate management of expectations, poor communication with family members and a process that prevents the best outcome for the patient”

Each of these experiences demonstrates the importance of the need for good communication, good quality of care, being responsive to people's needs- including carers, listening to carers and involving them in the discussions around an individual's care and keeping them informed of progress.

Recommendations

- 1) Having not been tasked with carrying out a targeted engagement activity around the policy, we have drawn on the evidence we already have to provide NEW Devon CCG with a response, which we hope will help to inform any changes to the policy going forward. It is evident through discussions with MNDA and from the CCG's response to our request for information that the people at the very heart of this process have not been invited to share their direct experiences of an application to CHC under the implementation of this interim policy.

In light of this, we would echo the response that MNDA has made to NEW Devon CCG, in that if NEW Devon CCG continue to implement the policy as it is, then they should ensure that those who are affected are fully consulted as to whether it has enabled / is enabling the person's care needs to be met, by way of choice, suitability and fully informed discussions.

- 2) We recommend that consideration is given to the suggested amendments to the policy that we have provided throughout our response.
- 3) We recommend that NEW Devon CCG allows enough time to fully consider the evidence that is being presented to them from Healthwatch Devon, MNDA, The South West Alliance of Neurological Organisations and the other contributors that we are not aware of, so that the policy is amended to reflect the experiences that have been shared and to ensure it is fit for purpose.
- 4) We recommend that NEW Devon CCG provides Healthwatch Devon with a report of the findings from this consultation and that following that, we are kept informed of progress as to how the policy develops going forward.

Appendix 1

A Request for Information to NEW Devon CCG



Healthwatch Devon
3 & 4 Cranmere Court, Lustleigh Close,
Matford Business Park, Exeter EX2 8PW

Tel: 0800 520 0640
Email: info@healthwatchdevon.co.uk
Web: www.healthwatchdevon.co.uk

Information Governance Team
NEW Devon Clinical Commissioning Group
Newcourt House
Old Rydon Lane
Exeter, Devon
EX2 7JU

Monday, 21 September 2015

For the attention of Lorna Collingwood-Burke:

REF: Healthwatch Devon Request for Information - Interim Choice Policy

Dear Lorna,

On the request of NEW Devon CCG, Healthwatch Devon is currently promoting the opportunity for people to have their say on the Interim Choice Policy for the provision of NHS Continuing Healthcare/ NHS Funded Care to adults.

We have published details of the policy review on our website. We have not however been requested to carry out any targeted engagement with those affected and therefore wish to seek assurance from the CCG that the people and families of those who have been affected by the interim policy, have been contacted directly for their contribution.

In addition, since publishing the details of the review, we have received concerns in relation to the length of time that has been allocated to carry out the review and that there has not been enough time to carry out targeted engagement with people who have experienced the process of CHC applications under the Interim Choice Policy.

In light of the above, Healthwatch Devon would like to request the following information from you, on behalf of NEW Devon CCG:

1. Please describe how NEW Devon CCG has engaged with people who have been through, or are going through the process of application for CHC / NHS funded healthcare. Have they been contacted directly for feedback?
2. Please provide details as to whether any direct / targeted engagement has been undertaken in respect of the interim policy, e.g. with healthcare professionals, or local

organisations supporting people with complex health needs, whose clients may have come into contact with the process under the interim policy?

3. Would NEW Devon CCG consider extending the deadline for feedback, to enable further engagement to take place?

For your information, Healthwatch Devon will be drafting a response to the review based on what we have heard from those who have contacted us directly about their experiences.

Given the short timescales, we would appreciate it if you could provide a response to these questions as soon as possible.

Many thanks in advance for your attention to this request for information from Healthwatch Devon.

Kind regards

Lorna

Lorna Davis
Information Officer
Healthwatch Devon

Appendix 2

NEW Devon CCG response to the Healthwatch Devon request for information

Newcourt House
Newcourt Drive
Old Rydon Lane
EXETER Devon EX2 7JQ

d-ccg.foi@nhs.net
Tel: 01392 205205

Ref: FOI717

16 October 2015

Dear Lorna,

Request for information under s.221 of the Local Government and Public Involvement in Health Act 2007 which was received on Monday 21 September 2015

You requested the following information.

- 1) Please describe how NEW Devon CCG has engaged with people who have been through, or are going through the process of application for CHC / NHS funded healthcare. Have they been contacted directly for feedback?**

NHS NEW Devon CCG has shared the policy with an invitation for comment from stake holders via email. We have also submitted an Engagement Gateway request with Healthwatch Devon asking for the policy to be shared with their networks and delivery partners this was on 29 June 2015.

There, has not been direct follow up, with patients and families as they are often in distressing circumstances with an un-well relative. However, we have responded to any concerns of complaints raised through the Patient Advice Liaison Services (PALS) and Complaints service. Following a referral for Continuing Healthcare (CHC) funding, whatever the outcome patients/families receive a letter detailing where they can direct any concerns. This is to the PALS teams. In response the CCG has had a few concerns raised. One of which is the wording on the actual letter, the letter has been amended. Another concern was with the language/terminology used in a provider organisation. The CCG followed this up with the provider and the use of appropriate language. A third was concerned over the availability of a care home package. Due to the geographical location of the patient, there was no choice of provider.

As part of the review process the CCG intends to produce a leaflet explaining CHC and the revised policy.

- 2) Please provide details as to whether any direct / targeted engagement has been undertaken in respect of the interim choice policy, e.g. with healthcare professionals, or local**

organisations supporting people with complex health needs, whose clients may have come into contact with the process under interim policy?

Contact with targeted professionals, yes, I can confirm as well as internal feedback, targeted professionals and organisations were contacted and invited to provide feedback. The CCG has received feedback and will be assessing this after the closure of the review period 19 October 2015.

3) Would NEW Devon CCG consider extending the deadline for feedback, to enable further engagement to take place?

Yes, this was undertaken to extend the review period by a further two weeks from 2 October to 19 October 2015.

Satisfaction

I trust this matter has been dealt with to your satisfaction but if there is anything which you need further clarification, please do not hesitate to contact the office on 01392 205205 or by email at d-ccg.foi@nhs.net Please remember to quote the reference number at the top of this letter in any future communications.

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you can write to the office and arrangements will be made for an independent review. You of course can write directly to the CCGs Chief Officer if you prefer using the “contact us” details displayed on the CCG website.

Appendix 3

MNDA response to NEW Devon CCG



Response to NEW Devon CCG interim Choice Policy for the provision of NHS continuing healthcare and NHS funded care for adults

Introduction

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. A third of people with the disease die within a year of diagnosis, and more than half within two years. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- iii. We welcome the opportunity to comment on the interim Choice Policy for the provision of NHS continuing healthcare/NHS funded care to adults which has been in operation by NEW Devon CCG for the past six months.
- iv. **We have serious concerns about the impact of the policy on the dignity and quality of life (and death) of people living with MND in Devon.** We take particular issue with the rule - or rule of thumb - that a person's preferred care package will normally be rejected if it exceeds by more than 10% the cost of the most cost effective care package (hereafter referred to as the 10% rule') (10.5.1.7).
- v. Cost-effective should, by definition, mean how effective a given care package is at meeting a person's needs in relation to its cost. However in the implementation of this policy, cost effective has come to mean cheapest. We have no reason to believe that this policy is being driven by anything other than a desire to cut costs, and we have seen it have a seriously detrimental impact on patient care.

- vi. The policy is also inconsistent with national guidance. This not only makes it confusing for people receiving care and their carers, it means both the policy itself and decisions taken under it could be vulnerable to judicial review. We strongly recommend that the CCG withdraw this policy with immediate effect.

Impact of the policy

- i. The impact of the policy was sharply felt by Mrs J, whose experience is provided below. This is the first direct experience the Association has of the policy so far, and it is highly illustrative of the detrimental effect it is having.

Mrs J's story

Mrs J was 64 years old and living with motor neurone disease when she was told that the budget for her care package had been reduced. She was living at home with her husband and main carer. She had an estimated 3-6 months left to live, and was facing the prospect of moving from her home into residential care, against her wishes.

On 11th May 2015 Mrs J received a visit from her case manager who explained to Mrs J that the budget for her care had been reduced from £1100 to £650 per week by the CCG, and as such, was £450 over the allocated amount. She was asked if she would consider moving into residential care, something Mrs J was very much against, as a great deal of money had been spent on home adaptation (wet room, recliners, ramps etc.) and she had an enduring wish was to remain in her own home. Mrs J and her carer were asked how they could remove support from their daily routine in order to make cost savings. Mrs J found this conversation extremely distressing, later describing herself as 'a blubbering wreck' during it. Mrs J's request for someone to explain the decision to her was denied by the CCG, who did not feel they had an obligation to provide this.

The reduction of carer hours in order to achieve cost savings began to impact on Mrs J's husband's ability to undertake shopping and other primary care roles. Being an elderly man with health problems of his own, Mr J's ability to care was physically and emotionally stretched. At this time Mrs J's physical functions were declining, impacting on her breathing and movement.

Mrs J sought the counsel of Tracy Thomas, MND Coordinator, who contacted the CCG to raise urgent concerns about the withdrawal of previously agreed support. She explained that during earlier conversations with Mrs J about care towards the end of life, 24-hour care at home was discussed and agreed to; at that stage she no reason to think this would not be available. She also outlined the distress and panic experienced by the couple at the prospect of Mrs J having to move into residential care against her wishes.

By mid-May Mrs J's condition had progressed to the point whereby a hoist was needed for all transfers around the home, requiring two carers to do this in a safe and dignified way. Faced with uncertainty, Mrs J expressed that she would rather

stop eating, than be forced into residential care against her wishes.

A response received from the CCG on 15th May stated that ‘the current care package was being funded’, but that ‘any increases in care package requiring additional funding will need consideration by the CCG as the request arises’. This response failed to acknowledge or address the fact that the package had already been reduced, as detailed above, so did not provide the clarity Mrs J desperately needed. The CCG expressed regret at the distress caused to Mrs J and her husband, though in the same sentence, said it be obliged to ‘demonstrate effective use of public money given the financial challenges of the CCG.’

At this stage Mrs J was unable to leave her house, or use her bathroom. She was at times left sitting on a commode when the carer had to leave, hair brushing and teeth cleanings were missed and carers did not have the time to take her out. Mrs J was spending eleven hours in bed each day, and if she soiled herself, would remain in that state until a carer eventually came to help. This physical deterioration and inadequate care was further compounded by the ongoing emotional distress caused by the uncertainty of her future situation.

The MND Coordinator continued to advocate for Mrs J throughout May 2015, pushing for improvement to the substandard care package and for a definitive answer about the future. Multiple emails and calls were made, all of which were redirected, or answered inadequately.

On the 22nd May 2015 it was agreed that Mrs J’s level of support would be reinstated to the point it was before, which came as a great relief. However not long after, in June, Mrs J’s growing needs meant that she required a larger package than she’s previously had (24 hours a day with double ups). Mrs J’s was informed that the CCG would only be able to fund this if it was within 10% of the safest, most cost-effective option unless there are exceptional circumstances, with alternative costings such as care homes having to be explored (as per the policy). An application would need to be made to the High Cost Panel.

An updated care plan reflecting Mrs J’s more complex and deteriorating needs was presented to the High Cost Panel on the 18th June 2015. On 25th June 2015 funding was granted for 24 hours home care.

On 20th August Mrs J died in her sleep. Far from meeting her healthcare needs and securing a dignified end of life for Mrs J, the CCG’s provision directly caused her final weeks to be undignified and full of distress.

Shared with the permission of Mrs J’s family.

Consultation questions

- i. The CCG has indicated that it seeks views on four particular aspects of the policy:
 1. The distance you travel for care
 2. The cost of care packages

3. How meaningful the current name of the policy is – “Choice Policy”
4. How easy the policy is to understand and which care groups it should cover

1. The distance you travel for care

- i. It is unclear what part of the policy deals with distance travelled for care, so this is difficult to properly address.
- ii. We know that residential care homes often lack the equipment and staff expertise necessary to look after someone with MND. This is particularly the case with people with MND and frontotemporal dementia, as many residential care settings are skilled in dementia care but not set up for MND care, or vice versa. So it is likely that the number of suitable placements available will be limited, and potentially limited to just one placement many miles from the person’s home. This means that a person could be required to move a long distance from their home as a result of the policy.
- iii. With poor transport links and elderly carers, family members may have limited access to their loved ones. Most people living with MND feel they need the support of their main carer, who understands their needs, is often still able to understand limited speech, able to feed the person in a way they feel comfortable with and be around constantly to support them. Not only are patients expected to leave their home, but risk losing their main support networks. In the case of Mrs J, she probably would not have had to move miles away, but as her husband did not drive, his journey would have likely involved taking two buses. This would have taken a toll on his own health needs.
- iv. As the document recognises, decisions made under the policy will need to be consistent with Article 8 of the European Convention of Human Rights - respect for a person’s private and family life. In Mrs J’s case, this would have been an extremely difficult case to argue.

2. The cost of care packages

- i. The crux of the policy is outlined on page 11

Where there is more than one suitable care package identified, an assessment of the total costs of each care package for overall cost-effectiveness and value for money will be made. Although there is no set tariff on expenditure, care packages where the cost exceeds the most cost-effective available package by more than 10% will not normally be funded.

and then on page 17

Subject to all above paragraphs in this section, NEW Devon CCG will fund a personal care package provided that: [...] the total cost of providing the home care package (to meet the person’s reasonable needs, as itemised within the care plan) is not more than 10% above the cost of the most cost effective care package identified by the CCG as meeting the individuals reasonable needs. Where the cost is above 10% the CCG will consider whether there are exceptional reasons for funding the care package.

- ii. It is unclear what ‘reasonable needs’ and ‘exceptional reasons’ look like in this context. Would a person’s wish to die at home be considered a reasonable need, and would honouring this wish be considered an exceptional reason for funding a care package? The list of considerations of exceptional circumstances listed at 10.11.2 does not list anything that should have already been part of the decision in the first place. The list rightly begins with consideration of the person’s wishes (10.11.2.1), but national guidance is quite clear that this should be the starting point for CHC decisions in all, not just in exceptional cases (see below).
- iii. We are also concerned about the move away from providing 24-hour care at home on the basis of cost. Page 16 the policy states

It must be understood that it is not possible to replicate support services that are available within NHS settings and registered care home facilities (e.g. 24 hour nursing care) and if this level of support is required it would not be possible to care for the person at home.

[...]

In cases where it is agreed to provide care in the person’s own home, the person and his or her family need to be aware that a time may come when it will no longer be appropriate or safe to provide care at home, for example if a deterioration in the person’s condition requires clinical oversight and twenty four hour monitoring.

- iv. Implementing a policy which rules out the possibility of 24-hour care at home is a significant departure from good practice. A wealth of national policy documents and initiatives over more than a decade have stated that practice should be directed at meeting more people’s preferred place of death, which is usually at home, and to provide care in all settings at any time day or night (see for example the National End of Life Care Strategy, DH, 2008 and NICE quality standard on end of life care for adults, NICE, 2011).
- v. NEW Devon CCG states that advance care planning – the process of formal decision making that helps patients make decisions about future care that take effect when they lose capacity, particularly at the end of life - as a key commissioning intention in its 2014 – 2016 Commissioning Framework. This policy endangers that ambition as the 10% rule limits a person’s set of choices at the end of life.
- vi. We are concerned with the statement at 4.1.8 that ‘It should be recognised that Advanced Directives are subject to review’. If this refers to the fact that *advance decisions* (the proper legal term) are subject to review by the person making them, this is correct, but it is difficult to see what the relevance is in this context. Advance decisions are legally binding and only extend to decisions to refuse life-sustaining treatment in the future. This should be clarified in the document.
- vii. Much progress has been made to achieving high quality person-centred care at the end of life both nationally and locally; this policy jeopardises that progress.

3. How meaningful the current name of the policy is – “Choice Policy”

- i. It is not at all meaningful. As Mrs J's case shows, choice is reduced not increased as a result of this policy.

4. How easy the policy is to understand and which care groups it should cover

- i. It is not at all easy to understand. The professionals we consulted with when forming this response had a difficult time understanding it; one can only imagine how much harder it would be for the person receiving care and their family members/ carers.
- ii. At points the policy is circular in its reasoning. For example, at 7.6 it states that "If a personal care package at home or Personal Health Budget is more cost-effective than a placement in a care establishment, it will only be proposed as the appropriate care package: [...] i) if the care package meets the pre-conditions and requirements set out in this policy." It is by no means clear what pre-conditions and requirements are being referred to and therefore how the decision will be made.
- iii. Similarly, section 6 quite rightly states that the policy must be consistent with Article 8 of the European Convention of Human Rights (respect for a person's private and family life), and that interferences with this right must be justified, but does not set out the circumstances under which a decision to move a person based on cost effectiveness of a care package would be permissible.
- iv. Finally, the crux of the policy - the 10% rule - is not revealed until page 11. If the aim is for the policy to be easily understood, this should be put front and centre.

Inconsistency with national guidance

- i. We would argue that the policy at best is not in the spirit of the national guidance on CHC, and at worst, directly contradicts it.
- ii. For example, the National Framework directly addresses the question of what limits (if any) can be put on individual choice where, if followed, this would result in a CCG paying for a very expensive care arrangement. It clearly states that the starting point for agreeing the package and care setting should be the individual's preferences. It goes on to describe the factors that must be considered by a CCG in the event that an individual's preference is for a more expensive package of care:

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

Where a person prefers to be supported in their own home, the actual costs of doing this should be identified on the basis of the individual's assessed needs and agreed desired outcomes. For example, individuals can sometimes be described as needing 24-hour care when what is meant is that they need ready access to support and/or supervision. CCGs should consider whether models such as assistive technology

could meet some of these needs. Where individuals are assessed as requiring nursing care, CCGs should identify whether their needs require the actual presence of a nurse at all times or whether the needs are for qualified nursing staff or specific tasks or to provide overall supervision. The willingness of family members to supplement support should also be taken into account, although no pressure should be put on them to offer such support. CCGs should not make assumptions about any individual, group or community being available to care for family members.

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

Gunter Case

84.1 In the case of *Gunter vs. South Western Staffordshire Primary Care Trust (2005)*, a severely disabled woman wished to continue living with her parents whereas the PCT's preference was for her to move into a care home. Whilst not reaching a final decision on the course of action to be taken, the court found that Article 8 of the European Convention of Human Rights had considerable weight in the decision to be made, that to remove her from her family home was an obvious interference with family life and so must be justified as proportionate. Cost could be taken into account but the improvement in the young woman's condition, the quality of life in her family environment and her express view that she did not want to move were all important factors which suggested that removing her from her home would require clear justification.¹

- iii. Contrast this with the CCG's 10% rule which requires there to be 'exceptional reasons' to fund the more expensive package, and the inconsistency becomes stark.
- iv. A further example of a contravention is found in the CHC Operating Model introduced by NHS England this year. A list of 'I' statements is provided to illustrate how individuals should experience the CHC process. The list includes:

I was confident that the professionals wanted to reach the correct decision, not the cheapest or more convenient one.

I have the care and support to meet my assessed needs, taking account of what has worked well for me in the past.

My needs are regularly reviewed and the focus of the review is on how my life is going and how well my support is working.

I understood how decisions were made and there was a contact who could explain the decision to me²

- v. Contrast this with Mrs J's experience of the policy. If Mrs J were alive today she would not recognise these statements as an accurate description of what happened to her. Test the proposed policy against these "I" statements and the 10% rule would have to be dropped.

¹ P. 107, *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*, DH, November 2012

www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf

² P. 36, *NHS England Operating Model for NHS Continuing Healthcare*, NHS England, March 2015
www.england.nhs.uk/wp-content/uploads/2015/03/ops-model-cont-hlthcr.pdf

- vi. The inconsistency of this policy with national guidance not only makes it even more difficult for people receiving care and their carers to understand, it means that both the policy itself and decisions taken under it could be vulnerable to judicial review.

See also

- i. The MND Association is a member of the South West Alliance of Neurological Organisations (SWANO), alongside MS Society, Parkinson's UK, Epilepsy Society and many others. SWANO will be submitting its own response to the consultation in addition to the individual members', and our response should be read alongside that.
- ii. We are pleased that the CCG has responded positively to SWANO's request for the deadline to be extended, as this will allow for greater feedback from neurological charities.
- iii. We remain concerned that the policy hasn't been well publicised amongst the people of Devon and that people like Mrs J are getting a shock when it finally comes to their attention. By this stage people are likely to be in a vulnerable position and potentially too unwell to challenge decisions. If a decision is taken to continue with this policy, the CCG should proactively inform those currently in receipt of CHC funding of the policy and give them an opportunity to and ask questions about how it might affect them.

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Appendix 4

Case Study: Crediton

My family's experience of dealing with Crediton Hospital and application of CHC funding for my father's ongoing care has been challenging. The issues are primarily about the inappropriate management of expectations, poor communication with family members and a process that prevents the best outcome for the patient.

My father had a stroke approximately 10 weeks ago (March 2014) and since being discharged from the RD&E has been in Crediton Hospital for rehabilitation. The first instance where the process did not support us as a family was when we requested to see my father's full notes. As a family we were keen to have a full understanding of my father's case. We were informed by the hospital that this was unusual and that would have to be considered. I was later informed that this would only be possible by putting a formal request in writing and that the Hospital only provided Care Home Managers and family members with a summary. It felt wrong. At the time, my father was deemed not to have mental capacity and therefore next of kin, my stepmother and I were therefore the ones that would be making decisions on his behalf. I would have anticipated a more forthcoming positive reaction however we did not pursue it any further as we didn't want to 'rock the boat'.

An initial assessment was carried out which indicated that my father should go through a full assessment for CHC funding. He was deemed not to have mental capacity. Therefore a full assessment meeting was planned with my stepmother and I, plus the team. On arriving for the assessment meeting, we were advised that they had seen a significant improvement with my father and therefore the team felt my father should be part of the process. We had also seen some improvements and so were quite comfortable with this although very aware that a meeting of that length would be exhausting and very difficult for my father given his fairly limited concentration span. The meeting is, by its nature, a difficult process for any family to go through. During the meeting issues were discussed openly and there was a mutually agreed level for each domain. Even before this meeting, we had already been told to look for vacancies in Nursing homes. Crediton Hospital had advised fairly early on that they did not believe they would be able to get my father much further forward and therefore we understood that we would need to find a place quite quickly. We had located a bed in a suitable home and were working towards this being achievable alongside the CHC application.

Various delays occurred and we started to worry that we would lose the bed as they would only keep it for a limited time. We were informed that the application had to be sent to North Devon not Exeter and staff were unsure when this panel met. To add to this a further delay occurred due to the lack of a psychiatrist's report. We were actually unaware that they needed this but it does make sense given that some of the key issues are about behaviour and cognition.

About 2 weeks later on a Friday, a member of the team who had not been present at the CHC meeting, announced to my stepmother whilst she was visiting my father that the team would not now be recommending CHC funding. This was with no prior consultation with us, the family. Surely the process of talking to the family and taking them through a 38 traumatic meeting to reach a mutually agreed conclusion should not be overturned in this way? Apparently the team receive input from external advisors, who have not even met my father and their judgement is that he does not meet certain criteria. The process is illogical, frustrating and detrimental to family welfare. I spoke to my stepmother after that announcement. She was extremely distressed. Her words were 'I can't face it any more; I never want to step foot inside that hospital again'. Dealing with families during

this process takes a high level of skill in effective communication and for my stepmother to leave the hospital in tears saying that she couldn't face visiting her own husband again is evidence that it was not handled well; in fact I think she has been treated appallingly. Naturally we asked why they had changed their minds. Apparently the team now believe his behaviour is entirely predictable and he is sleeping at nights. This is despite the fact that he has had a pattern of over-riding sleep medication every 4 days or so. I am genuinely surprised that they can be so confident that his behaviour is now not an issue.

To summarise:

1. We were not provided access to the case notes that potentially could have been helpful
2. The decision from the assessment meeting was not followed through. The recommendation was reversed in the space of 2.5hrs Friday afternoon and, to our knowledge, without any clinical assessment
3. There are continuing delays due to the lack of psychiatrist report
4. There are inconsistencies and inaccuracies, in our opinion, in the CHC application. The communication about this process is confusing, poor, and detrimental to getting the best outcome for the patient and distressing for the family.
5. The whole process is difficult because it raises the issue of finance at a time when families are struggling emotionally.
6. There are significant financial implications that we, as a family, need to address and therefore knowing the outcome of CHC, even though we appreciate that it can change (either way) is vital to the future financial planning not just for my father but also my stepmother. The priority is ensuring my father is in the best place for him regardless of where the paperwork is or who delays it further. I have been told by Crediton hospital that they should not discharge the patient until the CHC funding has been put to the panel.

Given the continuing delays, we were concerned that he would lose the bed that we had found for him. Coincidentally, my father was readmitted to the RD&E with a urinary tract infection. He is currently more confused but hopefully will return to his previous level of cognition prior to this. So to add to the issues, we now have to try and co-ordinate for his best welfare across two hospitals, two Trusts and a Nursing Home. On Saturday, I was told by Crediton Hospital that they would keep the bed until Tuesday, but my stepmother went in today, Monday and was given his belongings. We can understand the need to fill beds and if this is helping another person on the road to recovery, then of course it is the right thing to do. The issue is communication. I appreciate that staff are busy, I appreciate the great work that NHS staff do day in day out but by sharing this experience, I hope it can be used to improve the system for the future.