

Norfolk Health Overview and Scrutiny Committee

Date: **Thursday 23 February 2017**

Time: **10.00am**

Venue: **Edwards Room, County Hall, Norwich**

Persons attending the meeting are requested to turn off mobile phones.

Members of the public or interested parties who have indicated to the Committee Administrator, Timothy Shaw (contact details below), before the meeting that they wish to speak will, at the discretion of the Chairman, be given a maximum of five minutes at the microphone. Others may ask to speak and this again is at the discretion of the Chairman.

Membership

MAIN MEMBER

Vacancy

Mr R Bearman

Mr M Carttiss

Mrs J Chamberlin

Michael Chenery of
Horsburgh

Mrs A Claussen-
Reynolds

Ms E Corlett

Mr D Harrison

Mrs L Hemsall

Dr N Legg

Dr K Maguire

Mrs M Stone

Mrs S Weymouth

Mr P Wilkinson

SUBSTITUTE MEMBER

Mr P Gilmour

Ms Elizabeth Morgan

Mr N Dixon / Mrs S Gurney/
Mrs A Thomas/ Miss J Virgo

Mr N Dixon / Mrs S Gurney/
Mrs A Thomas/ Miss J Virgo

Mr N Dixon / Mrs S Gurney/
Mrs A Thomas/ Miss J Virgo

Mr G Williams

Ms S Whitaker

Mr B Hannah

Mr J Emsell

Mr C Foulger

Ms L Grahame

Mr N Dixon / Mrs S Gurney/
Mrs A Thomas/ Miss J Virgo

Mrs M Fairhead

Mr R Richmond

REPRESENTING

Norfolk County Council

Norfolk County Council

Norfolk County Council

Norfolk County Council

Norfolk County Council

North Norfolk District Council

Norfolk County Council

Norfolk County Council

Broadland District Council

South Norfolk District Council

Norwich City Council

Norfolk County Council

Great Yarmouth Borough
Council

Breckland District Council

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please contact the Committee Administrator:**

Tim Shaw on 01603 222948
or email timothy.shaw@norfolk.gov.uk

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1. To receive apologies and details of any substitute members attending

2. Minutes

To confirm the minutes of the meeting of the Norfolk Health Overview and Scrutiny Committee held on 12 January 2017.

(Page 5)

3. Members to declare any Interests

If you have a **Disclosable Pecuniary Interest** in a matter to be considered at the meeting and that interest is on your Register of Interests you must not speak or vote on the matter.

If you have a **Disclosable Pecuniary Interest** in a matter to be considered at the meeting and that interest is not on your Register of Interests you must declare that interest at the meeting and not speak or vote on the matter.

In either case you may remain in the room where the meeting is taking place. If you consider that it would be inappropriate in the circumstances to remain in the room, you may leave the room while the matter is dealt with.

If you do not have a Disclosable Pecuniary Interest you may nevertheless have an **Other Interest** in a matter to be discussed if it affects:

- your well being or financial position
- that of your family or close friends
- that of a club or society in which you have a management role

- that of another public body of which you are a member to a greater extent than others in your ward.

If that is the case then you must declare such an interest but can speak and vote on the matter.

4. **To receive any items of business which the Chairman decides should be considered as a matter of urgency**
5. **Chairman's announcements**
6. **10.10 – 11.30 Continuing healthcare** (Page 13)

An update on the implementation and evaluation of the new policy introduced by North Norfolk, South Norfolk, Norwich and West Norfolk CCGs.

Appendix A- CCGs report (Page 16)
Appendix B- Healthwatch Norfolk Evaluation (Page 92)
- 11.30 – 11.40 Break at the Chairman's discretion**
7. **11.40 – 11.45 NHOSC appointments** (Page 126)

To appoint a member to Great Yarmouth and Waveney Joint Health Scrutiny Committee and a link member for the James Paget University Hospitals NHS Foundation Trust
8. **11.45 – 12.00 Forward work programme** (Page 128)
- Glossary of Terms and Abbreviations** (Page 131)

Chris Walton
Head of Democratic Services

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Date Agenda Published: 15 February 2017



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**NORFOLK HEALTH OVERVIEW AND SCRUTINY COMMITTEE
MINUTES OF THE MEETING HELD AT COUNTY HALL, NORWICH
On 12 January 2017**

Present:

Mr R Bearman	Norfolk County Council
Mr M Carttiss (Chairman)	Norfolk County Council
Mrs J Chamberlin	Norfolk County Council
Michael Chenery of Horsbrugh	Norfolk County Council
Mr D Harrison	Norfolk County Council
Dr N Legg	South Norfolk District Council
Dr K Maguire	Norwich City Council
Mrs M Stone	Norfolk County Council
Mrs S Weymouth	Great Yarmouth Borough Council
Mr P Wilkinson	Breckland District Council
Mrs S Young	King's Lynn and West Norfolk Borough Council

Substitute Member Present:

Ms S Whitaker for Ms C Corlett

Also Present:

Ruth Kent	Primary Care Commissioning Officer, NHS England Midlands and East (East)
Sharon Gray	Contracts Manager, NHS England Midlands and East (East)
Suzanne Meredith	Consultant in Public Health, Norfolk County Council
Tony Dean	Chief Officer, Norfolk Local Pharmaceutical Committee
Lauren Seamons	Deputy Chief Officer, Norfolk Local Pharmaceutical Committee
Dr Tim Morton	Chairman, Norfolk & Waveney Local Medical Committee
Maureen Orr	Democratic Support and Scrutiny Team Manager
Tim Shaw	Committee Officer

1 Apologies for Absence

Apologies for absence were received from Mrs A Claussen- Reynolds, Ms E Corlett, Mrs L Hemsall and Mrs S Weymouth.

Apologies were also received from Mr C Walton, Head of Democratic Services.

2. Minutes

The minutes of the previous meeting held on 15 December 2016 were confirmed by the Committee and signed by the Chairman.

3. Declarations of Interest

3.1 There were no declarations of interest from members of the Committee.

3.2 Dr T Morton, Chairman, Norfolk and Waveney Local Medical Committee, who was a speaker for the item on Community Pharmacy declared an “other interest” because he was a Director of an Independent Pharmacy and his daughter worked for a Community Pharmacy.

4. Urgent Business

There were no items of urgent business.

5. Chairman’s Announcements

5.1 Colin Aldred

The Chairman said that he was sad to have to report to the Committee that Mr Colin Aldred had passed away this morning. Mr Aldred had joined the Committee as a County Council Member from the Great Yarmouth area in June 2013. He had also served as a Member of the Great Yarmouth and Waveney Joint Health Scrutiny Committee. Members stood in silent tribute to Colin’s memory and asked for a letter of condolence to be sent to his family at this sad time.

5.2 Paul Gilmour

The Chairman said Mr Paul Gilmour (the named substitute for Mr Aldred) had given his apologies for this meeting because he was recovering after undergoing knee replacement surgery at the Queen Elizabeth Hospital, King’s Lynn. Mr Gilmour had asked the Chairman to mention that the care and attention he had received from all staff on the Gayton Ward at the Queen Elizabeth Hospital was outstanding in every respect.

5.3 Mrs Annie Claussen-Reynolds

The Chairman said that Mrs Annie-Claussen-Reynolds (who had given her apologies for this meeting) had re-joined the Committee as North Norfolk District Council’s representative after a break of 6 months. Mr Glyn Williams was now the substitute member for North Norfolk District Council.

6 Community Pharmacy

- 6.1 The Committee received a suggested approach by Maureen Orr, Democratic Support and Scrutiny Team Manager, to information obtained from Norfolk County Council Public Health, the Norfolk Local Pharmaceutical Committee and Norfolk and Waveney Local Medical Committee about the local implementation of national reforms to the community pharmacy sector and the potential effect on services.
- 6.2 The Committee received evidence from Ruth Kent, Primary Care Commissioning Officer, NHS England Midlands and East (East), Sharon Gray, Contracts Manager, NHS England Midlands and East (East), Suzanne Meredith, Consultant in Public Health, Norfolk County Council, Tony Dean, Chief Officer, Norfolk Local Pharmaceutical Committee and Lauren Seamons, Deputy Chief Officer, Norfolk Local Pharmaceutical Committee. The Committee also heard from Dr Tim Morton, Chairman, Norfolk and Waveney Local Medical Committee, who declared an “other interest” in the subject before speaking in the meeting (see minute 3.2).
- 6.3 The following key points were noted:
- The Committee was informed by the speakers from the Norfolk Local Pharmaceutical Committee that there were several different types and sizes of community pharmacies, ranging from the large chains with shops that could be found on the high street, or in edge of city/ town supermarkets, to the small individually owned pharmacies often found in small rural communities. Some independent community pharmacies were open long hours when other health care professionals were unavailable and located at the heart of the most deprived communities in Norfolk.
 - It was pointed out that pharmacies were traditionally the facilitator of personalised care for people with long-term conditions; the trusted, convenient first port of call for episodic healthcare advice and treatment. However, the traditional role of the community pharmacist as the healthcare professional who dispensed prescriptions written by doctors had now changed.
 - In recent years community pharmacy had focused on the transition from a business model that relied predominantly on dispensing services, to one that was more reliant on providing an expanded range of clinical and public health services.
 - Many pharmacy contractors in Norfolk had invested significantly to meet the challenges of increasing clinical and public health service provision.
 - As a result of this investment, pharmacies were able to take on a much more visible and active role in improving the public's health through, for example, the provision of stop smoking services, sexual health services such as chlamydia screening, and involvement in immunisation services, including administration of vaccines, and were also taking on a crucial role in the treatment available to substance misuse patients.
 - This allowed for better integration and team working with the rest of the NHS.
 - Dr Tim Morton said that close working by GP and community pharmacy teams (particularly through the use of common IT systems) meant that the quality and standard of health service provided to the public was continually being improved. He added that the services provided by a dispensing pharmacy did not compare with the services that were available from a community pharmacy.
 - Dr Morton referred to a pilot scheme whereby GPs could apply for three years of financial support to integrate pharmacy into a GP practice after which time they would have to fund the full cost for themselves.

- Mr Dean said that the idea of a role for pharmacists within General Practice was welcome in principle but that reducing community pharmacy to pay for it was not welcome. The two roles were not the same.
- The speakers from NHS England Midlands and East (East) said that given the current pressures on other parts of the urgent and emergency care system, and particularly on GPs, community pharmacists were being encouraged to provide an alternative triage point for many of the common ailments currently dealt with by out-of- hour services and Accident and Emergency departments.
- Members said that the direction of travel for community pharmacy should be to encourage an expansion of the services that they provided and embed those services into NHS care pathways.
- The Committee was informed that the Norfolk Pharmaceutical Needs Assessment (PNA), published on behalf of the Norfolk Health and Wellbeing Board in 2015, had concluded that the number and distribution of pharmaceutical service provision in Norfolk was “adequate”.
- The Committee highlighted the importance of keeping the PNA (which was due to be reviewed every three years) up to date of changes required in the number and distribution of pharmaceutical service provision that arose because of planned new housing development. Suzanne Meredith said that she would look into the matter.
- It was pointed out that the funding settlement for community pharmacy in England from 1 December 2016 was explained in detail in the report. It was confirmed that there were 168 community pharmacies in Norfolk, 32 of which quality for the new Pharmacy Access Scheme (PhAS).
- Following the announcement by the Department of Health of the changes to the Community Pharmacy Contractual Framework for 2016-2018, the responsibility for implementation belonged to NHS England.
- The speakers said that there was no indication that funding for community pharmacy and funding for PhAS (to support patient access where pharmacies were sparsely spread and patients depended on them most) would continue beyond 2018. To be eligible for PhAS a pharmacy would have to meet set criteria, one of which was that it must be at least a mile away from its nearest pharmacy by road.
- It was pointed out that in addition to the PhAS scheme, pharmacists would be able to apply to participate in a Quality Payments Scheme that would reward community pharmacies for delivering quality criteria in all three of the quality dimensions: Clinical Effectiveness, Patient Safety and Patient Experience.
- One of the other proposed changes was the piloting of a national urgent medicines supply service, where people could be referred directly to community pharmacies after calling NHS 111.
- It was noted that the Norfolk and Waveney Sustainability & Transformation Plan (N&W STP) included a priority project for ‘Pharmacy support: employing pharmacists to work as part of the primary care team assisting with prescriptions, day-to-day medicine issues & consultations where appropriate’. Members suggested that the STP Executive Board should give careful consideration to how the changes in community pharmacy could impact on the N&W STP.
- The speakers from the Norfolk Local Pharmaceutical Committee (NLPC) said that the Secretary of State’s proposals could lead to free health services being withdrawn from community pharmacies. The biggest cuts to arise from the removal of Establishment Payments by the end of 2019/20 were likely to fall on low dispensing volume pharmacies in areas of Norfolk with the highest health needs.
- Pharmacists in Norfolk needed to have the business confidence in order to continue to invest.

- While large numbers of pharmacies were unlikely to close immediately, the NLPC expected that pharmacy owners would be forced to take steps to reduce their operating costs. These were likely to include reduced opening hours and staffing, and no longer providing the services which they were not obliged to provide, such as home delivery of medicines and the supply of medicines in compliance aids. They were concerned about the impact that this would have on patients with the result being that patients could find that they had to wait longer to receive the advice and support that was previously readily available.
- It was noted that there had been no public consultation about the changes and yet an estimated 3,000 pharmacies (a quarter of the total) in England might have to close as a result of the changes in funding.
- The High Court had granted the Pharmaceutical Services Negotiating Committee (PSNC) permission for two separate Judicial Reviews of the Secretary of State's October 2016 decision to implement cuts to community pharmacy funding and other changes. The PSNC believed the Secretary of State had failed to carry out a lawful consultation on the proposals for community pharmacy. The first hearing was expected to be heard in the week commencing 6 February 2017.
- The Committee noted that the changes to the community pharmacy contract were made nationally, and local commissioners (i.e. NHS England Midlands & East (East)) did not have the flexibility to respond to identified local issues. Around 90% of most community pharmacies' turnover was related to funding provided by NHS England in line with the contract. NHS England Midlands & East (East) had few resources for the commissioning of the 1,000 community pharmacies in this region, and no discretion in the operation of the national contract, including the application of PhAS. There was some local flexibility in relation to services commissioned from community pharmacy by others, such as Public Health and the CCGs.
- In the opinion of the Committee, the Department of Health had taken on a "London-centric" approach to community pharmacy that took little account of the geography of Norfolk and the impact significant savings reductions would have on the high quality of the community pharmacy services that were available in a rural county such as Norfolk.

6.4 The Committee **noted** the information contained in the report and that provided by the speakers during the meeting.

6.5 It was **agreed** that Maureen Orr, Democratic Support and Scrutiny Team Manager, should write to NHS England, NHS England Midlands and East, the Department of Health and the STP Executive Board regarding the concerns that Members of the Committee had about the future of community pharmacy.

6.6 It was also **agreed** that the draft letters should be circulated to Members for comment and final versions approved by the Vice Chairman before they were posted.

7 **Norfolk and Waveney Sustainability & Transformation Plan – NHOSC's comments**

7.1 The Committee received a report of comments made by Committee Members on 8 December 2016 that was presented for the Committee's approval before submission to Norfolk and Waveney Sustainability & Transformation (N&W STP) Executive Board Members.

- 7.2 The Committee **agreed** the list of comments contained in the report that were drawn from the minutes of its previous meeting subject to the following amendments (in italics):-

Point 2. – Breaking down barriers in the provision of care is fundamental to success, particularly between GPs and hospitals, physical and mental health and between health and social care. *This includes the barriers to the transfer of digital information between organisations.*

- 7.3 Point 6. – Providing greater public *and in-patient* access to therapies that tackle mental health issues at an early stage should be addressed as a strategic issue.

- 7.4 Point 3. – On being put to the vote, this point was removed.
There were five votes in favour and two votes against.

Dr K Maguire and Ms S Whitaker asked for it to be recorded in the minutes that they had voted against the removal of point 3 on the grounds that they considered this to be an important issue considered at the previous meeting.

- 7.5 An additional point was added:-

People with mental health problems do not have access to health services on a parity with the population as a whole, resulting in significantly shorter life expectancy and often inappropriate treatment. These inequalities should be addressed by integrating mental health with other services.

- 7.6 It was **agreed** that the amended list of comments should be submitted to the STP Executive Board.

8. Forward Work Programme

- 8.1 The Committee received a report from Maureen Orr, Democratic Support and Scrutiny Team Manager, that set out a proposed forward work programme for the remainder of 2016/17.

- 8.2 During consideration of this item a member of the public (who had not asked for her presence at the meeting to be recorded) with the permission of the Chairman asked where she could find details about any local stakeholder meetings on the Norfolk and Waveney STP. The member of the public was referred to the documents and means for raising issues about the STP that could be found on the Healthwatch Norfolk website and advised to raise the enquiry with them.

- 8.3 The forward work programme was agreed subject to:

As well as follow up action on the implementation of the Local Transformation Plan, the 'Children's mental health services in Norfolk' item scheduled for 6 April 2017 should include information about:-

- the services provided in Children's Centres;
- the output from the Children's Services Committee Task & Finish Group review of access to support and interventions for children's emotional wellbeing and mental health.

Chairman

The meeting concluded at 13:20 pm



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Continuing Healthcare

Suggested approach from Maureen Orr, Democratic Support and Scrutiny Team Manager

Examination of the effects of the new policy and guidance introduced by Norwich, North Norfolk, South Norfolk and West Norfolk Clinical Commissioning Groups in 2016 regarding the provision of NHS Continuing Healthcare.

1. Background

- 1.1 On 25 February 2016 Norfolk Health Overview and Scrutiny Committee (NHOSC) received a presentation from representatives of Norwich, North Norfolk, South Norfolk and West Norfolk Clinical Commissioning Group (the CCGs) on new policy, guide and procedure documents for delivering NHS Continuing Healthcare (NHS CHC). The policy, which was due to be implemented from 1 April 2016, set out the principles the four CCGs would apply in commissioning NHS CHC for patients who had already been assessed as eligible under the National Framework for NHS Continuing Health Care (Department of Health).
- 1.2 The National Framework, which the local CCGs did not change, defines for example:-
 - How screening is undertaken to identify people who may be suitable for an assessment of eligibility for NHS CHC –“the Checklist”
 - Processes for the assessment of eligibility undertaken through the completion of “ the Decision Support Tool”
 - Reviews of patients to ensure care continues to meet changing needs and that eligibility is reassessed at three months and then as a minimum annually
 - How interfaces with joint funding arrangements should be applied.

The local policy, guide and procedures aim to ensure fairness and equity in provision of CHC across the four CCG areas for patients who have been assessed as eligible under the National Framework.

- 1.3 On 14 April 2016 members were informed via the NHOSC Briefing that the implementation of the new local CHC policy was proceeding as planned. The following link (to North Norfolk CCG’s website) will take you

to the final version of the documents, which have been signed off by all four CCGs:-

<http://www.northnorfolkccg.nhs.uk/continuing-healthcare-chc>

- 1.4 NHS Great Yarmouth and Waveney CCG (GY&W CCG) did not adopt the same policy and guidance as the other four CCGs in Norfolk. GY&W CCG supports the provision of a clinically safe and sustainable package of NHS CHC to an individual in their own home where the anticipated cost to the CCG of such a package does not exceed the anticipated cost of suitable provision for that individual in a care home by more than 40%. In the event of a need to deviate from this policy, a panel is convened to discuss the request.

2. Purpose of today's meeting

- 2.1 In February 2016 NHOSC's main concerns about the new policy and procedures were about:-

- (a) Consistency of decision-making and service delivery across the four Complex Case Review Panels (CCRPs)
- (b) Waiting times for cases to be considered by the CCRPs
- (c) The outcome of the new policy in terms of whether patients who wish to (and are medically suitable to) receive CHC in their own homes are enabled to do so.

A service user who spoke at NHOSC on 25 February 2016 also raised the issue of need for a 'safety net' on occasions where the agency delivering healthcare fails to deliver for whatever reason, so that patients who received CHC at home can remain at home in those situations.

- 2.2 Representatives of the CCGs have been invited to attend today's meeting to discuss the implementation of the new policy in the past year, including the issues above. The CCGs' report is attached at Appendix A.
- 2.3 The four CCGs asked Healthwatch Norfolk (HWN) to undertake an independent evaluation of complaints and feedback from patients, family members and carers to look for any noticeable changes since the adoption of the new arrangements. HWN's evaluation report is attached at Appendix B and a representative will attend to present it.

3. Suggested approach

- 3.1 The committee may wish to discuss the following areas:-

- (a) The CCGs' report notes that in 2015-16 and the preceding years CHC appeals were incorrectly categorised as complaints. This changed in 2016-17, which means that the figures for complaints in the year are not directly comparable with previous years. Do the CCGs know whether the number of complaints (excluding appeals incorrectly categorised as complaints in 2015-16) has gone up or down in 2016-17?

- (b) Healthwatch Norfolk's report notes large disparity in average waiting time between CHC referral and assessment between the central CCGs and West Norfolk CCG as at September 2016. What are the reasons for such disparity?
- (c) The referral to assessment waiting times (as at September 2017) appeared to be much longer in West Norfolk CCG, where 16 patients had waited more than 6 months compared to 2 patients waiting that length of time across the other CCG areas. Is the process in West Norfolk different from the other areas?
- (d) Are the waiting times for cases to be heard by CCRPs recorded in each of the four CCG areas? Are there differences in the waiting times in the four areas?
- (e) Has the implementation of the policy made a difference in terms of the ratio of patients who receive NHS CHC in their own homes compared to those who receive it in a residential care setting in each of the CCG areas?
- (f) Are the CCGs assured that there is consistency of decision-making in terms of the way that CHC is provided across their four areas?
- (g) When considering the introduction of the new policy in early 2016 the CCGs decided to defer the implementation of one aspect:-

“A CCRP (Complex Case Review Panel) will ensure all domains are considered at the point where there is a more than 5% difference in the options for care being considered”.

They decided that the 5% difference rule would not be implemented until after the CCGs had evaluated the application of the new policy. Do the CCGs plan to enact this rule?

- (h) One of the CCGs' aims in introducing the new policy, guide and procedures was to make the CHC process clearer for patients, families and carers. Bearing in mind HWN's findings that there is a need for better communication around the CHC processes, what further improvements can the CCGs make?



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Norfolk Health Overview and Scrutiny Committee

Continuing Healthcare

1. Introduction and background

1.1. This report provides an update on the work conducted by members of the Continuing Care Operational Group from Norwich CCG, South Norfolk CCG, North Norfolk CCG and West Norfolk CCG to produce the following in 2015/16:

- NHS CHC Policy
- Procedures regarding CHC for NHS Staff
- Guide for patients and carers

- 1.2. On 25th February 2016, Norfolk Health Overview and Scrutiny Committee (NHOSC) received a presentation from the Rachael Peacock, Nick Pryke, Rosa Juarez and Laura McCartney-Gray on behalf of the four CCGs, Norwich, North Norfolk, South Norfolk and West Norfolk, regarding work on the open and transparent policy, guide and procedures documents for delivering NHS CHC to patients who have been assessed as eligible under the national framework for NHS Continuing Healthcare (Department of Health).
- 1.3. On 30th March 2016, the CCGs informed NHOSC that all CCGs had signed off the CHC Policy and published the final versions of the three documents on CCG websites (see Appendices 1, 2 and 3).
- 1.4. CCGs planned the detailed implementation of the policy during February and March 2016. Implementation of the policy commenced from 1st April 2016.

2. Implementation of the NHS CHC Policy

- 2.1. This policy includes the standardised process for the Complex Case Review Panel (CCRP) decision making and establishes norms in respect of when a CCG CCRP will convene to review a care package and what services NHS CHC should and should not fund.
- 2.2. CCG Governing Bodies approved the documents in January and February 2016 and planned to review the documents when the Department of Health (DoH) guidance was published later that year. In June 2016 the DOH updated the National Framework for NHS

Continuing Healthcare and NHS-funded Nursing Care to add a question to the decision support tool to find out if it is completed while the individual concerned is in an acute hospital setting. No amendments to the policy were necessary due to this minor change.

2.3. In planning the implementation of the NHS CHC Policy, CCGs decided to amend the proposed implementation of the following aspect of the “Standard Decision Making Framework and Governance Arrangements for CCGs When Commissioning and Reviewing NHS CHC Packages”:

- “A CCRP will ensure all domains are considered at the point where there is a more than 5% difference in the options for care being considered”.

2.4. This was due to CCGs agreeing that the application of the domains is best practice and requesting that CCRPs and the CSU apply these in all cases, regardless of whether there is a 5% difference in the options for care being considered. A standardised template was developed to support CCRPs in considering each domain in all cases.

2.5. Each CCG is required to have their own arrangements for decision making for patients they are responsible for. Norwich CCG track patients from the point of eligibility being established through to placement being made. This includes ensuring timely sign off at CCRP.

2.6. However, CCGs took a series of actions to ensure consistent decision making between the separate CCRPs in the four CCGs areas:

- Project management of the implementation of the NHS CHC Policy
- Collaborative development of CCRP Terms of Reference
- Providing CCRPs with access to the Guidance Sheet for Consideration of Human Rights in Complex Case Review Panel Decision Making (see Appendix 4)
- A standardised template was been developed to support CCRPs in considering each domain in all cases
- Offering appropriate training opportunities to CCRP members and CSU staff
- Adult Social Care staff were provided with a training/briefing session on the CHC Policy in July 2016
- CCGs commissioned Healthwatch to complete an evaluation of the impact of CCRPs’ use of the standardised decision making framework

- A number of training sessions for CCRP members and CSU staff were held between February and July 2016. This covered the NHS CHC Policy, Staff Procedures, Patient Guide, Harwood Charter and Operating Model "I" Statements.
- Additional training has been made available and is recommended for CCRP members from all CCGs in relation to equality, disability and human rights (including the panel chairman).
- The CSU provided a training plan for their staff detailing how the information from the Policy, Guides and CCRP domains would be cascaded. CCG staff assisted the CSU in delivering training to CSU staff.
- The CCGs also shared the presentation training materials (PowerPoint and evaluation) with the CSU to support them in this

3. Evaluation of the Standardised Process for CCRP Decision Making

- 3.1. The standardised process for the CCRP decision making introduced new arrangements for CCRPs. It was intended that this policy provide a consistent approach to reduce unwarranted variation for all patients and providers of NHS CHC across the four CCGs.
- 3.2. The CCGs and NEL CSU have worked closely with Social Care colleagues to implement the new policy.
- 3.3. CCGs committed to evaluating the impact of these changes on people's experiences of NHS CHC, particularly in respect of the number and type of complaints and appeals made by patients, family members and carers regarding decisions made about care.
- 3.4. CCGs commissioned Healthwatch to undertake the evaluation. The full report detailing is provided as part of this pack.
- 3.5. In summary, the report finds that the adoption of a standardised protocol for decision making about CHC by the four CCGs has not led to an increase in complaints, an increase in appeals or a reduction in expenditure. The findings indicate that there is a slight upward trend in the number of domiciliary packages for CHC patients, meaning more people are supported to remain at home when it is safe and clinically appropriate for them to do so. Fewer complaints about CHC have been made in the 2016/17 financial year, leading to fewer appeals. The report found that the nature of complaints has shifted slightly towards communication and funding issues, concluding that communication with patients, family members and carers on all aspects of NHS CHC could be improved.
- 3.6. The Healthwatch report shows a marked difference between the category of complaints received in 2015-16 and 2016-17. This is due in part to NEL CSU changing the way they categorise complaints

between 2015-16 and 2016-17. A review identified that historically CHC appeals were being incorrectly handled as complaints. This artificially inflated the number of complaints reported in previous years. CHC appeals are not complaints; they are a formal part of the CHC decision making process, and therefore do not fall within the remit of complaints. Clear changes were implemented from April 2016 to ensure each case received is managed through the correct pathway and in line with the patient/complainants wishes. In addition, some enquiries had previously been handled through the complaints process, rather than through a PALS type of approach. This has also since been remedied. These changes have resulted in a fall in CHC complaints for 2016/17. It may also be helpful to clarify that MP cases/complaints are where the MP writes to the CCG/CSU to raise concerns on behalf of his/her constituent. A complainant will otherwise send their complaint directly to the CCG/CSU. NHS complaints handling legislation does not apply to MP cases / complaints, and are therefore recorded separately.

3.7. Other key points to note are:

- No patients have moved nursing homes as a result of mobilisation through becoming eligible in a non-contracted home and the CSU Contracting Team confirmed this yesterday.
- No feedback has been received from social workers where a patient has refused a CHC assessment on the grounds that they are resident in a home that is not in contract with the CCGs and do not want to risk having to move.
- CCGs are currently in a very favourable position in terms of the number of residential and nursing homes in contract with the CCGs.

3.8. From the information that we have and the report provided by Healthwatch it is reasonable to state that there does not appear to have been any adverse impact.

4. Safety Netting for Patients Receiving CHC Funded Care

- 4.1. The CHC Policy and other documents produced do not specifically address the issue of safety netting as NHS CHC is a funding stream to support NHS long term care provision rather than a service to deliver care.
- 4.2. Services are purchased from private providers in Nursing and Residential Care settings, by Domiciliary Care agencies and more recently via carers directly employed by an individual under a Personal Health Budget arrangement.

- 4.3. Nursing and Residential Care providers and Domiciliary Care agencies have a responsibility to provide care but also to have plans in place covering contingency arrangements for sickness etc. Individuals may still access all mainstream health and social care support in case of short term breakdown in care. Where patients have a PHB contingency funds are allocated and patients assisted to make provision within their individual care and support plan.
- 4.4. Individuals in receipt of NHS CHC funded care have exactly the same rights as all other citizens under the Care Act including access to care in times of emergency. The NHS fund an array of care services round the clock for those in need of medical or nursing care in urgent situations. In a similar way the social care services provide round the clock, responsive services for those in need of urgent, short term, social care support. This includes individuals in receipt of NHS CHC funding.
- 4.5. CCGs will continue to explore opportunities to strengthen the integrated approach between health and social services, using existing resources to ensure care is delivered where needed regardless of funding stream.

5. Appendices

	Document Title	Document location
1	NHS CHC Policy	Attached
2	Central and West Norfolk Procedures for Staff on NHS CHC	Attached
3	Guide for patients and carers	Attached
4	Guidance Sheet for Consideration of Human Rights in Complex Case Review Panel Decision Making	Attached
5	Consideration of Domains in Complex Case Review Panel Decision Making	Attached
	An Evaluation of NHS Continuing Healthcare Arrangement and Feedback (Healthwatch Report)	Already included as part of the briefing pack provided by HOSC



*the Clinical Commissioning Groups
for North Norfolk, South Norfolk
Norwich and West Norfolk*

POLICY WITH REGARD TO NHS CHC CONTRACTS FOR CARE HOMES WITH NURSING AND RESIDENTIAL CARE HOMES

Date: 11/03/2016

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1. INTRODUCTION AND PURPOSE OF THIS POLICY

This Policy sets out the principles that the NHS Norwich Clinical Commissioning Group (CCG), NHS North Norfolk CCG, NHS South Norfolk CCG, and NHS West Norfolk CCG will apply in commissioning NHS Continuing Healthcare (NHS CHC). As such, this policy relates to care commissioned by:

- NHS Norwich CCG
- NHS North Norfolk CCG
- NHS South Norfolk CCG
- NHS West Norfolk CCG

This Policy is applicable to both new and existing patients eligible for NHS Continuing Healthcare. This Policy applies once an individual has received a comprehensive, multidisciplinary assessment of his/her care and support needs and the outcome shows that s/he has a primary health need and is therefore eligible for NHS Continuing Healthcare funding.

The content of the Policy represents policy strands that CCGs had developed within a guide. This is to ensure appropriate patient care and is in line with the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care November 2012 (Revised) ("the Framework"). It has been developed to provide a common understanding of the CCGs' commitments with respect to NHS CHC.

This policy ensures that:

- the patient's assessed NHS CHC needs will be met by the NHS
- patients will not pay for NHS services at the point of delivery
- patients are safeguarded

2. CONTRACTUAL ARRANGEMENTS AND PATIENT PLACEMENT

2.1. INTRODUCTION

This section outlines the approach being taken by CCGs in Norfolk to ensure continuity of care for patients eligible for NHS Continuing Healthcare (NHS CHC) as they introduce a new contractual model for care homes. This policy will apply to residential care homes but not to home care provision. For the purposes of clarity and consistency, references in this document to "care homes" includes both care homes with nursing and residential care homes.

This policy has been drafted in order to address a number of scenarios for which both CCGs and the Commissioning Support Unit require an agreed approach that can be implemented by the CSU contracts team.

Key principles:

- CCGs will only place patients with providers with whom they hold a contract for the provision of NHS CHC and which meets the quality and patient safety standards within that contract.
- Policies will seek to ensure that existing NHS CHC patients, insofar as possible, are not moved between providers or their historically-provided NHS funded care disrupted.
- Patients will be informed, prior to check-listing, of the contractual status of their current care provider. If the care provider does not hold an NHS contract and does not wish to hold one, for the provision of NHS CHC, options for alternative settings will be discussed with the patient and their families.
- Those providers that do not wish to provide NHS CHC will be enabled over time to withdraw from the market in a managed way.
- Where a patient lacks capacity to make decisions about their future care options, a best-interest meeting will be called and contractual options available considered.

For providers that have signed the new contract for provision of NHS CHC the contracts will be mobilised as normal. This will provide continuity of care for existing NHS CHC patients and choice for new patients seeking placements funded by NHS CHC. The quality standards within the new contracts will ensure that the CCGs can hold providers to account for the quality of care they provide and ensure that the most complex and vulnerable patients are well cared for.

2.2. SCENARIO PLANNING FOR PROVIDERS WHO NO LONGER WISH TO PROVIDE NHS CONTINUING HEALTHCARE AND PROVIDERS WHO ARE OUT OF AREA

Two scenarios have been identified for which a policy is needed:

- An approach with regard to existing care homes that are no longer choosing to provide NHS Continuing Healthcare under contract to the NHS with regard to:
 - Existing long standing NHS funded patients
 - Residents of non-contracted care homes thinking about the implications of being assessed for NHS CHC.
 - Newly eligible patients
- An approach with regard to provision of NHS CHC funded care outside the CCGs' areas.

2.3. CARE HOMES THAT ARE CHOOSING TO NO LONGER HOLD A CONTRACT FOR THE PROVISION OF NHS CHC

Providers that choose **not** to continue to hold a contract with the NHS for the provision of NHS CHC will not be made available on the choice menu for new NHS CHC funded placements.

2.4. WITH REGARD TO EXISTING NHS CHC FUNDED PATIENTS ALREADY ON NAMED PATIENT CONTRACTS WITHIN THESE CARE HOME SETTINGS, AT THE POINT AT WHICH THE CURRENT CONTRACT CEASES, OR FOR WHOM A DATE IS TO BE AGREED FOR THE IMPLEMENTATION OF THIS POLICY THE PROCESS WILL BE:

- Patients may choose to remain within a care home which is no longer willing to hold a contract for provision for NHS CHC. Where this is the case a discussion will be held with the provider. Those patients who wish to stay will be documented as a list of NHS CHC residents on a Named Patient document where the CSU/ CCG will endeavour to secure continuing placements for any existing NHS CHC patients at their current contracted prices. Such providers with named-patient arrangements will be reviewed annually, as a minimum. CCGs will still need to ensure that minimum CQC standards of care are reached and that there are no patient concerns or complaints about the standards of care being provided. The provider will still be required to deliver the care requirements of the NHS CHC package.
- Without a formal NHS CHC contract in place CCGs have few levers to apply to ensure actions are taken to improve care overall but any concerns would be communicated to the CQC; NHS funded patients may wish to reconsider their ongoing placement with that provider. Providers who do not hold an NHS Contract for NHS CHC will still be required to deliver a degree of reporting and will still be required to meet CQC standards for Care Homes.
- Individual patients who choose to remain in homes that do not wish to continue with an NHS contract for NHS CHC will be individually and clinically reviewed in line with normal NHS CHC patient review schedules for contracted providers. This can be monthly to annual reviews dependant on clinical need.
- Individual applications from non-contracted providers for inflationary uplifts will be considered by the CCGs whose patients are placed. These are unlikely if placements are above normal NHS CHC base rates.

- Existing NHS CHC Patients in non-contracted homes will be informed of the non-contractual status on review. Patients will be offered the option to move if they wish to and the options can be explored with them. In exceptional circumstances, where patients wish to stay in a non-contracted care home, and this is in the best interests of the patient, discussions with that care provider will be held to see if they will accept continuation of that patient's care provision under named patient arrangements.
- The intention is to reduce activity in non-contracted care providers as patients move, become no longer eligible or come to the end of their lives. This provides a managed transition for providers who wish to withdraw from NHS provision of NHS CHC. The CSU clinical teams have lists issued at regular intervals to ensure they know which care homes are signed up to an NHS Contract for the provision of NHS CHC and those that are not.
- Homes can seek to discharge a resident who is entitled to NHS CHC where they do not wish to continue to provide NHS CHC. In these cases all steps will be taken to support that patient and their family to find alternative provision. Patients may be under pressure to refuse NHS CHC funding and continue to self-fund. Staff need to be aware of this and ensure that patients are given all the advice and support they need to make the right decision for them.

2.5. WITH REGARD TO RESIDENTS IN NON-CONTRACTED CARE HOMES

Patients within non-contracted care homes should be given access to information on the potential outcomes of an eligibility assessment prior to check listing. Patients need to accept that unless an exceptional case can be made (e.g. patient is in end stage care or there is limited alternative provision available) they will be required to move to a contracted NHS CHC provider.

If the patient wishes to stay in a care home which does not provide contracted NHS CHC services, then the patient may choose to decline the checklist completion and the assessment of eligibility for NHS CHC funding and continue to self-fund or, if eligible, be funded by the Local Authority. Where patients choose not to proceed with a checklist and potential eligibility assessment this should be documented and signed off by the patient and the Local Authority informed if LA funded care is being provided. This can be reviewed by the patient at any time in the future and they can ask to be moved to a NHS CHC contracted care home at a later point in time and

funded by the NHS from the point they move. Patients would be given personal contact details for the CSU clinical team and their CCG in case they wish to review.

2.6. WITH REGARD TO PATIENTS IN NON-CONTRACTED CARE SETTING WHO BECOME NEWLY ELIGIBLE FOR NHS CHC

The following process would be followed:

- The provider would be asked again if they wish to take up an NHS standard contract for the provision of care to patients eligible for NHS CHC.

If the provider declines then the following steps are followed:

- The patient is given a choice of homes in the area that provide NHS CHC under contract, from which to choose a new care setting. Once the patient has chosen their preferred option to move then the CSU NHS CHC team will facilitate this with communications to both the sending and receiving providers. If a chosen provider has no bed available then arrangements will need to be agreed to meet the costs of care while the patient is awaiting the move.

Note: It is a patient's right to be assessed for NHS Continuing Healthcare funding eligibility and, if eligible, they have a right to have their care funded by the NHS. However it is not compulsory to take up the assessment, funding and provision on offer if a patient chooses not to. From time to time patients do seek not to pursue NHS CHC as they may wish to continue in accommodation than the NHS is not able to afford or contract for. A small number of care homes have contracted for the provision of NHS CHC but will be able to apply to offer patients options for additional services to meet wishes (not health needs). This may be attractive to some patients looking to move from wholly non-contracted providers (see "Additional Services policy" which is currently in development).

If the patient declines to move when the provider has refused to accept an NHS Standard Contract, a CCG joint panel may be convened to discuss a way forward. This will ensure due process has been followed, offer a peer review opportunity, explore options available and inform future policy development. Each CCG will nominate a representative to attend. The panel will be advisory. Decisions will remain the responsibility of the funding CCG. Meetings will be held as required and formally documented.

There will be rare and exceptional cases where the NHS CHC clinical team may, as a result of a best interest meeting, propose that a patient needs to stay in a particular setting (e.g. terminal phase of end of life care or where

alternative provision is unavailable). Such cases will be presented to the appropriate CCG for a decision accompanied with relevant risk assessments.

2.7. PATIENTS IN “OUT OF AREA” CARE HOMES

A number of patients are currently cared for close to family in other parts of the country but funded by Norfolk CCGs.

Occasionally, patients may be placed out of county where specific clinical needs cannot be met locally. CCGs are involved in decisions about out of area placements where the patient requires a specialist placement. These will be reviewed annually to ensure needs continue to be met appropriately.

Norfolk has historically offered this option in exceptional circumstances and these contracts have been inherited as long standing arrangements or agreed by CCGs as short term arrangements for terminal phase of end of life care and undertaken on a non-contracted activity (NCA) basis for the benefit of families.

It is proposed going forward that:

- These contracts be managed on a named patient basis as “non-contracted activity”.

Provider’s ongoing CQC registration would be monitored annually as a minimum via the national CQC website. The CSU is not currently resourced to physically visit the majority of NHS CHC patients placed out of area. Whilst teams may notify the local CCG of the presence of a Norfolk patient, many receiving areas are not set up to do anything with this information. The home in that area will register the patient with the local GP practice, enabling them to access local NHS services.

- Where a care home out of area is put under special measures or is closing, the Local Authority will generally contact all residents within that home. They will also contact those agencies that are funding care to notify them of the situation and the plan of action. Moves to alternative provision are normally handled in discussions with families, patients and commissioners by the Local Authority where the care home exists.

Example: This occurred in a care home in Lincolnshire where a care home closed and the residents were relocated in discussions with the patient, family, NEL CSU and the relevant CCG. The patient moved to a care home not far from the original setting in Lincolnshire at the same cost envelope.

- A placement with an out of area provider would be made based on an extended Individual Case Arrangement (ICA) which requires the provider to:

- Notify of any admission to hospital or death of the patient within 48 hours.
 - Notify commissioner of any safeguarding or results of best interest meeting with regard to our patient.
 - Notify commissioner of any complaints received from the patient and / or family and their response.
 - Invoice the correct CCG for the agreed amount monthly.
- Pricing would be at the local CCG rate for the area in which the care setting sits. This is historically and nationally what CCGs currently do. This enables each CCG area to maintain reasonable market stability even if it means that more is paid for placements in an area which has agreed higher than Norfolk weekly rates for NHS CHC patients or conversely the cost may be less if they have local rates than in Norfolk.
 - Families would be encouraged to let the CCG/ CSU in Norfolk know of any concerns regarding care home quality or problems as soon as possible so that discussions can be held with local services and registration bodies/ CQC. Contact information for their local commissioners would be provided.

Note: This out of area definition will apply to Great Yarmouth Nursing homes and residential homes that do not hold a contract with North Norfolk CCG, South Norfolk CCG, Norwich CCG, or West Norfolk CCG.

3. ADDITIONAL SERVICES CONTRACTS BETWEEN CARE PROVIDERS AND PATIENTS (AND/OR THEIR REPRESENTATIVES)

3.1. INTRODUCTION

This section has been developed to ensure that CCGs have a consistent and transparent approach to patients who wish to purchase additional services (over and above their assessed needs under NHS Continuing Healthcare). This is also intended to safeguard patients against unforeseen additional costs.

Additional Services, in this section refers to services which a patient who eligible for NHS CHC may choose to purchase directly from a Provider. These optional additional services must be over and above those identified as required to meet their Continuing Healthcare assessed needs. For clarity, this is distinct from social care arrangements which allow “top-ups”.

The relevant CCG will only provide and fund those services that are identified in an individual’s Complex Case Review Panel (CCRP) approved care plan and for which it has statutory responsibility.

3.2. ARRANGEMENTS FOR PATIENTS CHOOSING TO PAY FOR ADDITIONAL SERVICES

Patients may wish to make separate arrangements for additional services (such as aromatherapy, private garden area, manicures, sole use facilities which represent ‘wants’ not ‘needs’). Current case law supports this concept as acceptable. These additional services should be arranged and contracted for separately from the NHS contracts for NHS CHC services.

Patients are advised to inform CCGs in the first instance when they request additional services from a Provider. This is required to ensure patients are not paying for services to meet an assessed need.

Admissions into NHS CHC-funded care for nursing care, residential care or domiciliary care packages with a Provider are not conditional on a patient or their family entering additional services contracts.

Patients who cease any previously agreed additional services payment or contract should not be required to move to another nursing or residential care home following cessation of their contract for additional services. This does not exclude movement within a nursing home or residential care home.

An example of this would be where a nursing or residential care home has a luxury wing with rooms which have sole use private garden at a higher price than the NHS contracted rate. Under this arrangement, the NHS will pay the appropriate contracted rate and the patient will take out an additional service contract directly with the Provider for the sole use garden area on the understanding that if they become unable to pay for their the additional services then they would be moved to the standard NHS level of room within the same home.

The CCG does not accept liability for any failure by patients or families to pay for additional services, or upon cessation (either by the patient or Provider) of the additional services contract.

Patients must be made aware of the arrangement and consequences of cessation of their additional services contract by the Provider from the outset. This should be communicated in a professional, timely and transparent manner.

The commissioners will make an appropriate referral (e.g. to Adult Safeguarding, CQC, counter-fraud) if a provider is found to be charging for additional services and either:

- the services are not in place
- the amount of the charges outweighs the additional services being provided
- fraud or abuse is suspected

3.3. INFORMATION FOR PATIENTS, FAMILIES AND CARERS

Information explaining additional services must be clearly written and shared with patients and carers by the Provider. Patients and/or their representatives are required to sign to confirm that they understand and accept their private contractual arrangements regarding additional services and the consequences of cancelling any additional services payment agreement between themselves and the provider.

Failure of the Provider to communicate the nature, content and terms of the contractual arrangement to patients and/or their representatives, will result in CCGs/CSU making an appropriate referral as above.

4. STANDARD DECISION MAKING FRAMEWORK AND GOVERNANCE ARRANGEMENTS FOR CCGS WHEN COMMISSIONING AND REVIEWING NHS CHC PACKAGES

This section has been developed to provide a common understanding of the CCGs' commitments with respect to the funding of packages of care to meet an NHS CHC eligible individual's assessed health and associated social care needs.

This section is intended to assist the CCGs standardise the quality and consistency of care, and make decisions about clinically-appropriate care provision for individuals in a consistent way.

CCGs have identified the need for a clearly articulated policy regarding the commissioning and review of NHS CHC care packages. The key aim is to inform robust and consistent commissioning decision making by the CCGs using a locally developed standardised decision-making framework. This section relates to a standardisation of decision making on care packages for patients who are eligible for NHS CHC across all CCGs. Standardising governance arrangements will support CCGs in their oversight and decision making with regard to funding of individual NHS CHC packages of care.

The following norms are established in respect of when a CCG Complex Case Review Panel (CCRP) will convene to review a care package and what services NHS CHC should and should not fund:

- A CCRP will ensure all domains are considered at the point where there is a more than 5% difference in the options for care being considered
- Agreement of standard list of services which CHC packages will fund, and those which they won't (standard list of services on page 14 of Appendix I).

The following are standard domains that CCG CCRP's will take into consideration when making decisions regarding individual packages of care for patients eligible for NHS CHC:

- Patients' needs and the outcomes they wish to obtain from their care
- Patient and family preferences and views
- The Human Rights Act and any other Disability Rights legislation (see Appendix J)
- Clinical and safeguarding risks and patients/ families views on these. (Patient view would apply where a patient fully understands risks in the choices they would like to make but still wishes to take those risks.)

- The price and affordability of the various options for the provision of care in light of the need to ensure equitable use of limited NHS resources.
- Due to geographical gaps in some care services, panels will have to take into account the availability of services and choices for patients as this is a limiting factor for many. Reviews of current provision are taking into account current gaps in services in order to support commissioners to fill these.

Decisions regarding the setting of personal health budgets will be treated in the same way.

All existing NHS CHC patients will go through a review process, either at 3 months post eligibility decision, or annually. At that point for any home care packages in excess of the 5% of the equivalent Care Home package, a CCG CCPR will be convened to review the package of care taking into account the domains set out above. The CCRPs will be cognisant of the 5% figure but also required to take all of the other factors set out above in agreeing a care package, and reflect any exceptionality in circumstances.

This approach will be clearer for patients and families, result in CCGs having a more consistent approach, allow CCGs flexibility to reflect the unique nature of care packages and individual needs and ensure CCGs treat all patients fairly and comply with the law.

5. EXCEPTIONAL CIRCUMSTANCES

In exceptional cases, the relevant CCG, having regard to the individual's assessed health and associated social care needs, may be prepared to consider funding a package of care where the anticipated cost to the CCG is more than it would usually expect to pay; or elements of the care package are not usually funded from NHS CHC budgets.

The Commissioner recognises that exceptional circumstances may require exceptional consideration but will retain its obligation to make best use of NHS resources. Exceptionality will be determined by the relevant CCG on a case by case basis. The grounds for and appropriateness of exceptionality will be determined by the merits of each case by the Commissioner.

Exceptionality may include (but it not limited to):

- the provision of a care package to an individual who has an advanced, progressive, incurable illness;
- those cases in which consideration must be given to address the particular cultural and/or communication needs of the individual;

- those cases in which consideration must be given to address the particular clinical and/or physiological needs of the patient and/or the risks associated with meeting their needs
- those cases in which an individual in an existing out of area placement becomes eligible for NHS Continuing Healthcare and wishes to continue to be accommodated out of area.

In addition the CCGs recognise that there will be cases in which, as a consequence of the nature of the needs of the individual in that particular case, it may be necessary to fund a higher cost package of care for a limited period of time (for example, in cases where a high/intense level of staffing needs to be put in place to set up the care package). In such cases the CCG may be prepared to consider funding the higher cost package of care for a limited period of time.

6. REVIEW OF THIS POLICY

NHS Norwich CCG, as the coordinating commissioner, owns this policy. The policy sections will be reviewed as set out below. However, each time a section is reviewed, the full document must be reviewed to ensure consistency.

Section 1: Contractual Arrangements and Patient Placement

This section is to be reviewed in the first instance, by the CCG joint panel in six months on the basis that all parties will have more experience of working with patients and providers to see if this policy is working. Out of area placement arrangements will be reviewed as part of a wider discussion between CCGs and CSU regarding all patients placed out of area and how we can better monitor at a distance or resource the travelling.

Section 2: Additional Services contracts between care providers and patients (or families) for patients in receipt of NHS Continuing Healthcare

Review of this section will be annual or on receipt of relevant additional case law or guidance.

Section 3: Standard Decision Making Framework and Governance Arrangements for CCGs when commissioning and reviewing NHS CHC packages

Review of this section will be within 6 months of January 2016. This will be submitted to HOSC and CCGs' GB meetings.

7. APPENDICES

Reference	Document title	Document location
1. Contractual Arrangements and Patient Placement		
A	Flow Chart	Appendix A - Flow chart.docx
B	Contract Offer Letter 1	Appendix B - Contract offer letter 1.docx
C	Contract Offer Letter 2	Appendix C- Contract offer letter 2.docx
D	Checklist Waiver	Appendix D - Checklist waiver.docx
E	Assessment Waiver	Appendix E- Assessment waiver.docx
Section 2: Additional Services contracts between care providers and patients (or families) for patients in receipt of NHS Continuing Healthcare		
F	Mills and Reeve summary	Appendix F - Mills and Reeves Summary.docx
G	Contract Variation	Appendix G - Contract Variation.docx
H	List of Additional Services	Appendix H - List of Additional Services.docx
Section 3: Standard Decision Making Framework and Governance Arrangements for CCGs when commissioning and reviewing CHC packages		
I	Central and West Norfolk Procedures for Staff on NHS CHC V11 (Final)	..\..\CHC Policy Development\Central and West Norfolk Procedures for Staff on NHS CHC V 11 (Final).docx
J	Guidance Sheet for Consideration of Human Rights in Complex Case Review Panel Decision Making	Appendix J- Guidance Sheet for Complex Case review Panels.docx
K	Consideration of Domains in Complex Case Review Panel Decision Making	..\..\CHC Policy Development\Complex Cases Panels\2016.03.09 CCRP - Decision MakingTemplate for Complex Case Review Panels (FINAL).docx
L	Central and West Norfolk Guide to NHS CHC for patients V 21 (Final)	..\..\CHC Policy Development\Central and West Norfolk Guide to NHS CHC for patients V 21 (Final).docx



*the Clinical Commissioning Groups
for North Norfolk, South Norfolk
Norwich and West Norfolk*

**Central and West Norfolk CCG Procedures for NHS Staff in relation to NHS
Continuing Healthcare**

Date: 11/03/2016

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1. Introduction to NHS Continuing Healthcare

1.1. What is the purpose of this document?

The purpose of this Guide is to provide information for NHS staff about the provision of NHS Continuing Healthcare (NHS CHC) in Central and West Norfolk. This relates to NHS CHC for adults only.

Providing this information will help NHS staff understand the complexities of the national and local processes, as well as the limitations that might apply.

This document is organised in the form of frequently asked questions. It is designed so that you can print off specific sections that you may be interested in.

This information will be kept up to date so that staff will be more informed and have the opportunity to gain a better understanding of the procedures and processes that apply. This Guide will also provide links to other more detailed guidance for those who wish to access it.

1.2. What is NHS CHC?

NHS continuing healthcare means a package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a 'primary health need'. Such care is provided to an individual aged 18 or over to meet needs that have arisen as a result of disability, accident or illness.

NHS CHC can be provided in a range of settings; from care in your own home, nursing homes, supported living, group home arrangements or in specialist care units. Care arrangements for NHS CHC are managed via the NHS CHC Brokerage Team or through a Personal Health Budget, subject to formal approval by CCGs.

Prior to considering referral into the NHS CHC pathway, NHS staff are advised to consider all other mainstream service options that may be appropriate for patients. These may include, but are not limited to:

- Local authority Social Services
- Volunteer organisations
- Assistive technology

The Department of Health has produced a public information leaflet on NHS Continuing Healthcare and NHS-funded Nursing Care:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/193700/NHS_CHC_Public_Information_Leaflet_Final.pdf

1.3. What frameworks govern NHS Continuing Healthcare and NHS-Funded Nursing Care?

The two key documents that NHS staff should have a relevant understanding of in relation to NHS Continuing Healthcare for adults are:

- The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf
- *NHS England Operating Model* for NHS Continuing Healthcare:
<https://www.england.nhs.uk/wp-content/uploads/2015/03/ops-model-cont-hlthcr.pdf>

The Association of Directors of Adult Social Services (ADASS) has produced three documents to support health professionals to understand the principles and implementation of the National Framework for NHS CHC.

1. Guide for Health and Social Care practitioners:

<https://www.england.nhs.uk/wp-content/uploads/2015/04/guide-hlth-socl-care-practnrs.pdf>

2. Explaining the NHS Continuing Healthcare process:

<https://www.england.nhs.uk/wp-content/uploads/2015/04/chc-process-public-guid-practnr.pdf>

3. Quick Reference Guide to the National Framework:

<https://www.england.nhs.uk/wp-content/uploads/2015/04/qck-ref-guid-chc-nat-framwrk.pdf>

1.4. What do NHS Staff need to be aware of in relation to NHS CHC?

1.4.1. The Harwood Care and Support Charter

The Charter sets out principles for how care providers should work to ensure people are at the centre of their care. Being a Charter signatory demonstrates to people using services that an organisation or individual is committed to ensuring people who receive care and support services in Norfolk have the high quality services that they want.

The Harwood Care and Support Charter was produced with input from people who receive care and support services, carers and representatives from organisations providing care and support in Norfolk.

Signatories to the Charter are committed to:

- listening to people and responding to their needs;
- treating people with respect, dignity and courtesy;
- making sure people are not left unsupported;
- telling people how much services cost and how to access financial assistance;
- making sure staff are properly trained and Police checked;
- reporting back to commissioners where things work well or could be developed to better meet needs.

1.4.2. NMC Code of Conduct

The Code presents the professional standards that nurses and midwives must uphold in order to be registered to practise in the UK.

Effective from 31 March 2015, this Code reflects the world in which we live and work today, and changing roles and expectations of nurses and midwives. It is structured around four themes – prioritise people, practise effectively, preserve safety and promote professionalism and trust. Developed in collaboration with many who care about good nursing and midwifery, the Code can be used by nurses and midwives as a way of reinforcing their professionalism. Failure to comply with the Code may bring their fitness to practise into question.

Further information available at: <http://www.nmc.org.uk/standards/code/>

1.4.3. Safeguarding Adults

Safeguarding is preventing the physical, emotional, sexual, psychological and financial abuse of adults who have care and support needs, and acting quickly when abuse is suspected. It can also include neglect, domestic violence, modern slavery, organisational or discriminatory abuse. Norfolk County Council Adult Social Services is the lead agency for Safeguarding Adults.

Within Norfolk, all referrals should be made to 0344 800 8020, which is a 24 hour number.

If the patient is receiving care outside of Norfolk, then a Safeguarding referral can be by contacting the County Council for that area.

It is the professional responsibility of all those involved in co-ordinating and providing an individual's care, to play an active part in safeguarding them from harm or abuse.

1.4.4. Capacity Assessments under the Mental Health Act

The patient's mental capacity must be established at key points in the NHS CHC process, taking in to account that capacity is both time and decision specific. As such, capacity should be considered when seeking consent to undertake relevant stages of the assessment, including capacity to refuse or deny access to records held by other agencies. Additionally, a patient may not have capacity to make decisions with regard to how their care needs can be met,

The Mental Capacity Act 2005 (MCA) provides a statutory framework to empower and protect vulnerable people who are unable to make their own decisions. The initial assumption will be that adults have capacity to make all or some decisions, unless it is shown that they cannot. The MCA clarifies the rights and duties of the workers and carers, including how to act and make decisions on behalf of adults who may lack mental capacity.

Where the health professional involved in facilitating the NHS CHC assessment or arranging the package of care suspects the individual may not have the Mental Capacity to accept, refuse or choose amongst options, it is their responsibility to undertake a mental capacity assessment, in accordance with the Mental Capacity Act 2005 and the National Framework for NHS CHC.

Where a patient lacking capacity has no family or friends to support the decision making process, a suitable person from the Independent Mental Capacity Advocate (IMCA) service or a suitable person from other local advocacy services, should support when:

- A decision is being made about serious medical treatment, or a long term change in accommodation
- The patient lacks capacity to make that decision
- The patient does not have friends or family with whom the decision maker feels is appropriate to consult with about the decision.

In a situation where the patient lacks capacity to make a decision, it is the responsibility of the health professional to make and document a best interest's decision. This should consider all of the options that would be available to the patient if they had capacity and should take in to account the views of those advocating on the patient's behalf, along with others involved in the delivery and planning of their care. In some situations where the decision is significant or challenged, it may be appropriate to undertake this within a best interests meeting.

1.5. Deprivation of Liberty

In some cases, a best interests decision may be made to provide a package of care that restricts the patient's freedom to come and go unsupervised (continuous supervision) or where physical barriers are in place to prevent them leaving their care setting (locked doors/bed rails). Where this restriction arises it could be considered to be a Deprivation of Liberty and as such, will require authorisation

through the relevant routes. When a patient's needs are met in a CQC registered domicile (Hospital, Nursing Home, Residential Home) it is the responsibility of the provider to make DoLS applications via the local authority. However, in cases where a patient is being deprived of their liberty in a non-CQC registered domicile (supported living/own home), it is the responsibility of those arranging the care to make application to the Court of Protection.

1.6. How is eligibility for NHS CHC established and reviewed?

The initial checklist assessment can be completed by a nurse, doctor, other healthcare professional or social worker. Patients should be told that they are being assessed and have their informed consent obtained.

Depending on the outcome of the checklist, patients will be told that they don't meet the criteria for a full assessment of NHS Continuing Healthcare and are therefore not eligible for a full assessment, or will be referred for a full assessment of eligibility. Being referred for a full assessment doesn't necessarily mean that a patient will be eligible for NHS Continuing Healthcare. The purpose of the checklist is to enable anyone who might be eligible to have the opportunity for a full assessment.

The professional(s) completing the checklist should record written reasons for their decision, and sign and date the checklist. Patients should be given a copy of the completed checklist. You can download a blank copy of the [NHS continuing healthcare checklist from GOV.UK \(PDF, 168kb\)](#).

Full assessments for NHS continuing healthcare are undertaken by a "multi-disciplinary" team (MDT) made up of a minimum of two health or care professionals who are already involved in a patient's care. Patients should be informed about who is coordinating the NHS CHC assessment.

The team's assessment will consider patients' needs under the following headings:

- behaviour
- cognition (understanding)
- communication
- psychological/emotional needs
- mobility
- nutrition (food and drink)
- continence
- skin (including wounds and ulcers)
- breathing
- symptom control through drug therapies and medication

- altered states of consciousness
- other significant needs

These needs are then given a weighting marked "priority", "severe", "high", "moderate", "low" or "no needs".

The multi-disciplinary team will consider:

- what help is needed
- how complex these needs are
- how intense or severe these needs can be
- how unpredictable they are, including any risks to the person's health if the right care isn't provided at the right time

If the patient has at least one priority need, or severe needs in at least two areas, they should be eligible for NHS Continuing Healthcare. Patients may also be eligible if they have a severe need in one area plus a number of other needs, or a number of high or moderate needs, depending on their nature, intensity, complexity or unpredictability.

In all cases, the overall need, and interactions between needs, will be taken into account, together with evidence from risk assessments, in deciding whether NHS CHC should be provided.

The assessment should take into account the patient's views and the views of their carers. Patients should be sent a copy of the decision documents, along with clear reasons for the decision.

You can [download a blank copy of the NHS continuing healthcare decision support tool from GOV.UK](#).

Eligibility will be reviewed at 3 and 12 months following establishment of eligibility for NHS CHC, as a minimum. These reviews ensure that the care package remains relevant to the patient and meets their assessed needs. There is a possibility that patients will be found ineligible.

Potential outcomes following ineligibility for NHS CHC may include eligibility for NHS-funded Nursing Care being established, which could make a contribution towards meeting a health need in a residential care setting. If patients are found ineligible for either NHS CHC or NHS-funded Nursing Care, they will be referred to the local authority.

Patients who wish to appeal the decision should contact the Appeals Department at the contact details outlined in "How can patients appeal the eligibility decision?".

1.7. Is there an NHS CHC pathway for patients with ‘a rapidly deteriorating condition which may be entering a terminal phase’?

In these circumstances an ‘appropriate clinician’ may complete a Fast Track Pathway Tool. Once completed, the documentation will be sent to the NHS CHC Clinical Team for immediate review and action if eligible. This will include the clinical information required to arrange the appropriate placement/package of support as soon as possible (usually within 48 hours).

1.8. How are NHS staff involved in the decision-making process for patient care?

NHS Staff will be involved through requests for input into the MDT process. This could be in the form of attendance to the MDT meeting or submission of a report. NHS Staff should only be involved in a patient’s MDT if they are knowledgeable about the patient or have undertaken an assessment of that patient’s needs. NHS Staff should also have undertaken relevant and appropriate training on NHS CHC.

The decision will be based on factual, contemporaneous information (i.e. up to date and within 3 months) and recorded within the DST.

1.9. How will the decision about eligibility be made and communicated to patients and relevant NHS staff?

The recommendation for eligibility or ineligibility will be made by the MDT and communicated verbally at the time the DST is completed. An MDT should not leave a meeting with a patient without informing them of what the recommendation is. Following the conclusion of the MDT, the recommendation is submitted for ratification (agreement or approval) to the relevant CCG.

Following ratification of a decision for eligibility or ineligibility, the patient will receive a letter informing them of the decision and a copy of the DST. This letter should include details of what happens next for patients and their families; it also provides contact details. If a patient is found to be ineligible for NHS CHC, this will be communicated formally to the local authority.

1.10. What does the NHS CHC funding cover?

Patients who are eligible for NHS CHC have complex needs that can be met from a wide variety of services (NHS, local authority and Voluntary Sector). The following

table outlines a list of services and describes whether they are available from NHS mainstream services or NHS CHC budgets.

In order to ensure equity of provision and fair use of resources, careful consideration has been given to what can be included within a package of care for a patient who is eligible for NHS CHC.

The following table is a guide to what can be funded by NHS CHC and what can be provided from mainstream NHS services. Please note: for a Personal Health Budget, the table below will be used to calculate the value of that PHB. Once the value has been established, the individual will have choice and control over choosing services to meet their health need, subject to agreement with the CCG and ensuring existing services are fully utilised. This is clarified further in section 2.5.

Service	Is this service available within mainstream NHS provision?	Is this service available within an NHS CHC budget?	Referral Guidance
Domiciliary care	No	Yes. Available from locally contracted providers.	Contact NHS CHC Brokerage Team.
Planned care to replace informal care provision	No	Yes – if identified following care review	Referrals can be made to local authority for a carers assessment. Referrals can also be made to NHS CHC Brokerage Team for care review if circumstances change.
Additional unplanned care to replace informal care provision	Yes – short term urgent support is available via Local Authority.	No – except in exceptional circumstances.	Referrals can be made to local authority
Carer advice and befriending services	No	No	Referrals can be made to local authority and information is available on the Norfolk County Council website. The Carers Agency Partnership has a helpline and website.

Physiotherapy	Yes	No – except in exceptional circumstances.	In exceptional circumstances CHC funding may be used to train a family or paid carer to undertake certain activities such as passive movements and exercises to help to maintain function and relieve pain.
Occupational Therapy	Yes	No	Referrals should be made to mainstream OT services.
Speech and Language Therapy	Yes	No	Referrals should be made to mainstream SALT and Dysphagia Services.
Podiatry	Yes	No	Referrals should be made to mainstream podiatry services.
Advocacy	Yes	No	Refer to mainstream Advocacy services.
Transport	Yes, but only to and from medical or clinical appointments if a person meets the eligibility criteria for the transport.	No – except in exceptional circumstances.	If family are unable to support, referrals should be made to NHS mainstream transport services, local authority transport services, DWP, voluntary and community sector. NHS CHC cannot be used to purchase vehicles.
Assistive technology - smart house technology and safety equipment	Yes	No	Referrals to Norfolk Community Health and Care or local authority Social Services.
Standard Equipment (including pressure care)	Yes	No	Referrals to Integrated Community Equipment Services (ICES).
Bespoke equipment (including pressure care)	No	Yes	Referrals to NHS CHC Brokerage Team.
Respiratory support equipment (e.g. ventilators)	No	Yes	Referrals to NHS CHC Brokerage Team.

Wheelchairs and seating systems including electric and outdoor chairs	Yes	No	Referrals to Wheelchair Service.
Equipment for leisure and social activities (e.g. swimming gear or horse riding boots).	No	No	Patients will self-fund or pay for rental of equipment.
Day services	No	Yes	Referral to local authority Social Services.
Computers, laptops, Wi-Fi and Broadband	No	No – except exceptional circumstances	Referral to NHS CHC Brokerage Team. If considered, rental from third party only.
Major adaptations to housing and environment	No	No	Referral to local authority District Councils.
Specialist foods and fluids	Yes - if provided on prescription.	No	Referral to GP.
Hearing and low vision services	Yes	No	Referrals can be made to specialist services.
Gardening, domestic and window cleaning	No	No	Referrals to local voluntary organisations.
Path clearance to aid access	No	No - except in exceptional circumstances	Referrals to NHS CHC Brokerage Team.
Falls assessments	Yes	No	Referral to mainstream services.
Palliative care and end of life services	Yes	Yes	Referral to NHC CHC Brokerage Team.
Continence services	Yes	No	Referral to mainstream services.

In exceptional cases, and where there is clear evidence to support health benefits, the NHS may be prepared to consider funding a package of care where the anticipated cost is more than it would usually expect to pay; or where elements of the care package are not usually funded from NHS CHC.

1.11. What are the arrangements for patients choosing to pay for additional services?

NHS CHC funding is only available to cover the care required to meet a patient's assessed needs.

Patients may wish to make separate arrangements for additional services directly with the provider (such as aromatherapy, private garden area, manicures, sole use facilities which represent 'wants' not 'needs') and current case law supports this concept as acceptable. These additional services should be arranged and contracted for separately from the NHS contracts for NHS CHC services.

Admissions into NHS CHC-funded care for nursing care, residential care or domiciliary care packages with a Provider are not conditional on a patient or their family entering additional services contracts.

Where patients are considering entering into arrangements for additional services, it is advisable that they contact the NHS CHC Brokerage Team for advice (e.g. a nursing home may request a financial contribution for laundry costs which should be included within the NHS CHC care package).

2. Planning and Commissioning of NHS CHC

2.1. How is a patient's care planned once they are assessed as eligible for NHS CHC?

Once a patient's eligibility for NHS CHC is established, a care package to meet each individual patient's needs has been agreed. The planning of the patient's care will be based on the documentation received from the MDT professionals. An Individual Case Arrangement (ICA) form will be used to identify the patient's needs, list and mitigate risks and detail care delivery.

The NHS CHC Brokerage Team is responsible for coordinating the planning of a patient's care. They will engage with the patient, their family and/or representatives as well as health professionals in considering the options for the provision of services to meet a patient's assessed needs. The focus of the planning is to secure improved outcomes for the individual.

The NHS CHC Clinical NHS CHC team can provide information on:

- Lists of care providers with NHS CHC contracts
- Nursing home information with regard to CQC compliance
- Day services
- Local voluntary schemes and support in local communities
- Equipment and NHS wheelchairs

If patients are currently in receipt of local authority funded care and become eligible for NHS CHC, the NHS CHC team will do their best to facilitate continuity of care.

There may be issues which make this difficult (e.g. the service provider may not be willing to sign an NHS contract). If this happens the NHS CHC team will work with the patient to seek alternative services to meet their individual needs.

2.2. How are decisions about the funding of patients' care packages made?

Once the NHS CHC Brokerage Team have recommended a package of care to meet a patient's assessed needs, and an ICA form has been completed, this will be presented to the relevant CCG's Complex Case Review Panel (CCRP). The CCRP meets on a regular basis to approve the care to be offered under NHS CHC to meet each individual patient's needs.

Some norms have been established in respect of when a CCG Complex Case Review Panel (CCRP) will convene to review a care package and what services NHS CHC should and shouldn't fund. Specifically:

- A CCRP will ensure all domains are considered at the point where there is a more than 5% difference in the options for care being considered
- Secondly a standard list of services which NHS CHC packages will fund, and those which they won't.

CCRPs will take the following domains into consideration when making these decisions:

- Patients' needs and the outcomes which they wish to achieve from their care
- Patient and family preferences and views on the choices available
- The Human Rights Act and any other Disability Rights legislation
- Clinical and safeguarding risks and patients'/families views on these (Patient view would apply where a patient fully understands the risks in the choices they would like to make but still wish to take those risks).
- The price and affordability of the various options for the provision of care in light of the need to ensure equitable use of limited NHS resources.
- Panels will have to take into account the availability of services and choices for patients as this is a limiting factor for many. Reviews of current provision are taking into account current gaps in services CCGs are looking to try to fill.

The following evidence base will be compiled by NHS CHC Clinicians to aid CCRP members in considering the domains listed above:

- Care plans
- Risk assessments
- Assessments tools (e.g. Waterlow Score, MUST, falls risk, behaviour charts)
- Brokerage form
- CCRP form
- Individual Case Arrangement

CCRPs will be focused on patient care. Both CCRP members and NHS CHC staff will be knowledgeable of the following:

- Human Rights Act 1998
- Disability Rights legislation
- Equality Act 2010
- The UN Convention on disability rights
- The Harwood Care and Support Charter
- Part A “I” statements from the NHS England Operating Model for NHS Continuing Healthcare

Please see the appendix for the links to each of these.

2.3. Are there any limiting factors with regard to patient’s care packages?

The NHS CHC Brokerage Team can only arrange NHS CHC care packages with Providers who have signed up to NHS Standard Contracts and who have available capacity. Despite this, there may be occasions when the NHS CHC team are unable to arrange care packages with these providers. This may be due to:

- Concerns regarding the quality of care
- Safeguarding concerns
- The provider is unable to safely deliver the care required to meet the patient’s needs
- The provider does not have capacity or coverage in the area
- Financial dispute

2.4. What is a personal health budget?

A personal health budget is a monetary allocation to an individual patient to support their identified health and wellbeing needs. The aim is to give people with long-term conditions and disabilities greater choice and control over the healthcare and support they receive.

Personal health budgets work in a similar way to the social services-funded personal budgets that many people are already using to manage and pay for their social care.

Together with the NHS CHC Clinical team, patients or their representatives will develop a care plan that sets out their personal health and wellbeing needs, the health outcomes they want to achieve, the amount of money in the budget and how they are going to spend it. Personal health budgets can be used to pay for a wide range of items and services, including day services, personal care and equipment.

2.5. What can a patient spend their PHB on?

- There is no “set menu” of services a PHB can be spent on, as each person is unique.
- However, each PHB-holder will need to ensure they have used their PHB to meet the identified care needs of the CHC-eligible person. This means if a person was identified as needing a certain number of hours a day for care, it would be expected the PHB would be used to meet that care.
- PHBs do encourage innovation and choice, and this could include using the PHB for services and activities. If this is the case, the PHB-holder will need to explain the benefit to the person’s health, and this will need to be agreed by the relevant CCG.
- A PHB may not be used for equipment without first checking with the relevant OT and with the Integrated Community Equipment Service, as this is something which has already been funded.
- A PHB may be used for transport to activities, provided the PHB-holder can demonstrate the benefit to the health of the person. PHBs will not be used to cover the maintenance / insurance of a vehicle. It is suggested any transport costs are allocated a sum of money which will then be reviewed.
- PHBs cannot be used for the daily cost of living – this includes food, utility bills (unless in exceptional circumstances e.g. live-in carers), and cleaning / gardening services
- PHBs should be used to provide full insurance cover, costs of being an employer (including pensions) and support as needed.

2.6. Is there a process for out of area placements?

CCGs will consider individual requests for commissioning care outside of area as part of the CCRP decision making process outlined in 2.2. In exceptional circumstances such as for end of life care, CCGs can consider placements out-of-area. However, CCGs cannot fund care outside of the UK.

If patients move to another county, their responsible CCG will remain the same. Reviews of eligibility are arranged by the NHS CHC teams with the relevant CCG.

2.7. Can family members continue to provide care as part of a patient’s NHS CHC care package?

Families and friends who are actively involved in the provision of care are very much part of the care planning and delivery. Care plans start with the care that the family are able and willing to provide.

Training and equipment can be provided to support carers in the safe provision of care.

If families are providing elements of care, they need to agree the care plan, approve it and be clear about who to notify if they are suddenly unable to provide it.

3. Reviewing care and eligibility for NHS CHC funding

3.1. What happens if the patient's needs change?

Should family members, carers or other health professionals believe the care package is no longer relevant to the patient or does not meet their assessed needs, they should contact the NHS CHC Team and request a review of the package of care as soon as possible.

3.2. What happens if upon review, the patient is found to be ineligible for NHS CHC funding?

The process for reviewing a patient's care is in line with the National Framework; all patients who are eligible for NHS CHC are reviewed, as a minimum, three months following initial eligibility and thereafter at least annually. The process for defining ineligibility is exactly the same as the process for agreeing eligibility (as outlined in 1.5).

If a patient is found to be ineligible for NHS CHC there are four possible outcomes:

3.2.1. Care and support no longer required

If a patient is found to be ineligible for NHS CHC, funding for care will cease 28 days following the date of ineligibility.

3.2.2. Care and support is required and patients self-funds

If the local authority decide that the patient will transfer to self-funding for their ongoing care, responsibility for meeting these costs will be transferred within 28 days following the date of ineligibility. Patients or named individuals with power of attorney will be notified of this in writing and given a contact point for any individual queries.

3.2.3. Care and support is required and patient is eligible for NHS-funded Nursing Care

For patients who still have a health need, they may be eligible for NHS-funded nursing care. This provides a nationally agreed contribution to the funding of care

needs and is paid directly to the nursing home. NHS-funded nursing care is administrated by the local authority. For enquires about NHS-Funded Nursing care please use contact details below:

NHS Funded Nursing Care

Room 614

Sixth Floor

County Hall

Martineau Lane

Norwich

NR1 2SQ

3.2.4. Care and support is required and patient is eligible for local authority funding

For patients transferring to social services support, the assessment of a patient's ongoing needs will be completed by the local authority within 28 days. For enquiries contact:

Adult Community Care- Norfolk County Council

Norfolk Care First

Tel: 0344 800 8020

3.2.5. How can patients appeal the eligibility decision?

Regardless of the possible outcome, patients who wish to appeal the decision should contact the Appeals Department at the contact details shown below.

If patients wish to lodge an appeal they will need to submit their reasons for disagreeing with the decision. This should contain new or previously unseen evidence. An appeal must be lodged within 6 months of notification of the eligibility decision, in line with the National Framework.

If a member of NHS Staff is supporting a patient through the appeals process, they should refer the patient to the "Central and West Norfolk CCGs Guide to NHS Adult Continuing Healthcare", which contains a detailed description of the process.

Appeals Department

NEL CSU

Lakeside 400

Old Chapel Way
Broadland Business Park
Thorpe St Andrew
Norwich
NR7 0WG

4. Providing feedback and getting in touch

4.1. How can NHS Staff provide feedback on their experience of services and help to improve them?

If staff want to tell us about NHS CHC services which have not met their expectations, they can contact the NHS CHC Team via the Single Point of Access e-mail:

NELCSU.CHCClinicalTeam@nhs.net

Staff are also able to:

- Escalate via line manager
- Escalate to Safeguarding
- Escalate to the patient's CCG
- Escalate to NHS England

4.2. How do patients complain if they are not happy with their care or experience of the NHS CHC pathway?

Patients can contact the NEL CSU Complaints Team directly via:

nelcsu.angliacomplaints@nhs.net

The CSU Complaints Team will log the complaint and send a letter acknowledging its receipt within 2 working days. An investigation will then take place and on (or before) working day 25, the person will be sent a letter detailing the outcome.

NHS Staff may be contacted for input during the investigation to ensure that the Investigation Officer has a full picture of the complaint.

4.3. What should NHS Staff do if they have further questions?

E-Learning for NHS CHC

NHS England, in conjunction with the Association of Directors of Adult Social Services (ADASS) have launched an electronic training tool for all those involved in assessment and decision making around NHS CHC.

The tool, fully endorsed by the Department of Health, was developed by staff working within this complex policy area from the NHS, Adult Social Care and patient representative groups.

The tool is free to use and is designed to be intuitive and flexible so that health and social care staff can easily register and undertake training at a time and place that suits them. The tool will support local training programmes and support the work undertaken by all CCGs to ensure that there is consistency and legal compliance in the assessment and decision making processes for NHS Continuing Healthcare.

For NHS Staff, the E-Learning tool is available at:

<http://www.e-lfh.org.uk/projects/nhscontinuinghealthcare/>

For Local Authority Staff, the E-Learning tool is available at:

<http://nhscontinuinghealthcare.e-lfh.org.uk>

For enquiries about NHS Continuing Healthcare please contact:

Continuing Healthcare Department

NELCSU

Lakeside 400

Old Chapel Way

Broadland Business Park

Thorpe St Andrew

Norwich

NR7 0WG

Email: ANGLIACSU.CHCClinicalTeam@nhs.net

Tel: 01603 257 243

For enquiries regarding Retrospective Claims please contact:

Retrospective Continuing Healthcare Department

NELCSU

Lakeside 400

Old Chapel Way

Broadland Business Park

Thorpe St Andrew


Norwich

NR7 0WG

Email: ANGLIACSU.RetrospectiveClaims@nhs.net

Tel: 01603 257 284

5. Appendices

Appendix	Document title	Document source
1	NHS CHC Information Sheet	 CHC Information Sheet.pdf
2	The Human Rights Act 1998	http://www.legislation.gov.uk/ukpga/1998/42/contents
3	Further information on Disability Rights	https://www.gov.uk/rights-disabled-person/overview
4	Equality Act 2010	http://www.legislation.gov.uk/ukpga/2010/15/contents
5	The UN Convention on disability rights	http://www.un.org/disabilities/convention/conventionfull.shtml
6	The Harwood Care and Support Charter	http://www.norfolk.gov.uk/view/NCC117232
7	Part A - "I" statements from the NHS England Operating Model for NHS Continuing Healthcare	https://www.england.nhs.uk/wp-content/uploads/2015/03/ops-model-cont-hlthcr.pdf
8	Consideration of Domains in Complex Case Review Panel Decision Making	Complex Cases Panels\2016.03.09 CCRP - Decision MakingTemplate for Complex Case Review Panels (FINAL).docx



*the Clinical Commissioning Groups
for North Norfolk, South Norfolk
Norwich and West Norfolk*

**Central and West Norfolk Guide to NHS Adult Continuing Healthcare for
patients and their carers**

Date: 11/03/2016

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1. Introduction to NHS Continuing Healthcare for Adults

1.1. Purpose of the Guide

This guide contains information for patients, carers and families about NHS Continuing Healthcare (NHS CHC) in Norfolk (excluding Great Yarmouth and Waveney.). This is the area covered by the NHS Clinical Commissioning Groups (CCGs) for Norwich, North Norfolk, South Norfolk and West Norfolk.

This information should help patients, their carers and families to understand the national and local NHS CHC processes, as well the choices available to them.

The guide comprises a number of frequently asked questions regarding NHS CHC and the answers to these. It also provides signposting to more detailed guidance.

1.2. What is NHS Continuing Healthcare?

NHS CHC is the name given to a package of care for adults aged 18 or over, which is arranged and funded solely by the NHS.

In order to receive NHS CHC funding, a person has to be assessed according to a legally-prescribed decision-making process to determine whether they have a 'primary health need'.

A person can receive NHS CHC in a variety of settings, including their own home or a care home. NHS CHC is free, unlike support provided by local authorities for which a financial charge may be made depending on income and savings.

If a person is eligible for NHS CHC, this means that the NHS will pay for their healthcare and associated social care needs.

There are two national documents that patients and their carers or families may wish to consult for further information. These are:

- A. **The NHS National Framework for Continuing Healthcare and NHS-Funded Nursing Care:** defines the way that eligibility is assessed and established. This ensures fair and consistent access to NHS funding across England, so that people eligible for NHS CHC and with similar needs have an equal likelihood of getting all of their health and social care provided by the NHS. This is available via the GOV.UK website at:

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

- B. **The NHS England Operating Model for NHS Continuing Healthcare:** sets out the strategic importance of NHS CHC and the arrangements for NHS England to be assured that CCGs are complying with the National Framework. This is available at:

<https://www.england.nhs.uk/wp-content/uploads/2015/03/ops-model-cont-hlthcr.pdf>

1.3. What is the process for deciding whether a person is eligible for NHS Continuing Healthcare?

To be eligible for NHS CHC, a person must have a 'primary health need'. This means their need for care is primarily due to their health needs and is determined by a team of healthcare professionals (known as a multi-disciplinary team). A primary health need is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided.

Once eligible for NHS CHC, a person's care will be funded by the NHS. This is subject to regular reviews, and, if a person's care needs change, the funding arrangements for their care package may also change.

The process for establishing if someone is eligible includes the following steps:

A. Referral for initial checklist

The purpose of the checklist is to decide whether a person should be given a full assessment for NHS CHC. A professional involved with a person's care may refer them for the initial checklist. A person can also make their own request to be referred.

The checklist can be completed by a nurse, doctor, other healthcare professional or social worker. People should be told that they are being assessed and be asked for their consent. Being referred for a full assessment does not necessarily mean that a person will be eligible for NHS CHC.

The professional(s) completing the checklist should record written reasons for their decision, and sign and date the checklist. The person whose needs are being assessed should be given a copy of the completed checklist. A blank copy of the [NHS continuing healthcare checklist from GOV.UK \(PDF, 168kb\)](#).

B. Full assessment for NHS CHC

Full assessments for NHS CHC are carried out by a "multi-disciplinary" team, made up of a minimum of two health or care professionals who are already involved in a person's care. A person should be told who is coordinating their assessment.

The team's assessment will consider a person's needs under the following headings:

- behaviour
- cognition (understanding)

- communication
- psychological/emotional needs
- mobility
- nutrition (food and drink)
- continence
- skin (including wounds and ulcers)
- breathing
- symptom control through drug therapies and medication
- altered states of consciousness
- other significant needs

The team will consider:

- what help is needed
- how complex these needs are
- how intense or severe these needs can be
- how unpredictable they are, including any risks to the person's health if the right care is not provided at the right time

The assessment should take into account a person's own views and the views of any carers. The person being assessed should be given a copy of the decision documents, along with clear reasons for the decision.

A blank copy of the NHS continuing healthcare decision support tool is available from GOV.UK: <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

1.4. What happens if a person becomes eligible for NHS CHC while in receipt of self-funded or local authority-funded care?

If a person is already resident in a nursing home or residential care home (either self-funded or local authority-funded), they will be told before the checklist stage whether their home has an NHS Standard Contract.

The relevant NHS Clinical Commissioning Group will only arrange care packages with homes that have a valid Standard Contract for NHS CHC.

If the person wishes to stay in a care home which does not provide contracted NHS CHC services, they may choose to decline the checklist completion and the assessment of eligibility for NHS CHC. These patients will continue to self-fund or, if eligible, will be funded by the local authority.

If a person already receives local authority-funded care and becomes eligible for NHS CHC, the NHS CHC team will do its best to facilitate continuity of care. There may be issues which make this difficult, for example: the provider may not be willing to sign an NHS Standard Contract. If this happens, the NHS CHC team will explain what alternative services are available to meet a person's needs.

1.5. What arrangements are in place for palliative and end-of-life care?

There is an NHS CHC pathway for patients with a rapidly deteriorating condition which may be entering a terminal phase. In these circumstances, a health professional may consider it is appropriate to complete a Fast Track Pathway Tool. Once completed, the documentation will be sent to the NHS CHC Clinical Team for immediate action. This will include the clinical information required to arrange the appropriate placement/package of support as soon as possible (usually within 48 hours).

1.6. How does a person appeal if they not deemed eligible for NHS CHC?

If a person wants to appeal, they will need to submit the reasons why they do not agree with the decision, along with any new or previously unseen evidence to support their statement. An appeal must be lodged *within 6 months* of notification of the eligibility decision, in line with the National Framework. The aim is to complete the appeal process within *3 months* of receipt of an appeal. The NHS will not fund a person's care package during the appeals process. To begin the process the person appealing should write to:

Appeals Department

NEL CSU

Lakeside 400

Old Chapel Way

Broadland Business Park,

Norwich

NR7 0WG

Further information on appeals is available in the NHS CHC Information Sheet (Appendix 2).

1.7. What can a person expect in the planning and commissioning of their care?

Once eligibility for NHS CHC is established, a care package to meet their needs is agreed. Care planning will be based on the documentation received from the multi-disciplinary team.

The NHS CHC Brokerage Team is responsible for coordinating the planning of a patient's care. They will engage with the person, their family and/or representatives, as well as health professionals, and draw up options for providing services that meet the person's needs. Options are dependent on what services are available in local areas.

In the following circumstances, it may be appropriate for NHS CHC services in the person's own home to be withdrawn and provided in a different setting:

- the situation presents a risk of danger, violence, or harassment of staff who are delivering the care package;
- the NHS considers that the level of clinical and/or safeguarding risk to the individual has become unacceptable and cannot be safely managed;
- the clinical risks of providing care in a specific environment are considered too high – a full risk assessment must be made covering all the assessed needs and reflecting the proposed environment in which the care is to be provided. A person can choose to accept clinical risks but if the cost of managing that risk is too high, the NHS in certain circumstances may not agree to fund this option;
- the person who wishes to receive care at home does not have a full understanding of the risks and possible consequences. In these circumstances a 'best interest' meeting may be convened or a mental health capacity assessment made;
- the organisations contracted to provide safe care cannot do so ;
- the patient's primary care team feels it cannot provide adequate medical cover.
- the family/person with whom the person normally lives feel they cannot cope. If action by family members or friends is needed to provide elements of care or to manage risks, they must also agree to the care plan. An example of this would be the care of a patient with behavioural difficulties as a result of brain trauma who needs to be cared for in a quiet environment where activities are highly structured. This cannot be provided by some families within the family home so the risk is that the person's health will deteriorate and the care plan at home will fail;
- actions to minimise risks will include those that must be taken by the person in receipt of care or their family – an example of this is where a person with severe breathing difficulties is returning to a family home where relatives

smoke. Relatives need to agree to refrain from smoking, and the risks need to be explained to the patient if they choose to receive care in that environment.

1.8. How are decisions about the funding of a person's care package made?

Once a person's eligibility for NHS CHC is established, a care package has to be agreed. The person and their family will be involved with other health professionals in considering the available options.

Complex Case Review Panels (CCRPs) make decisions about the care to be offered under NHS CHC to meet a person's needs. In agreeing the funding for a person's care, they will take into account:

- A person's needs and the outcomes which they wish to achieve from their care
- Preferences expressed by a person and/or their family, and their views on the choices available
- The Human Rights Act and any other Disability Rights legislation
- Clinical and safeguarding risks and the views of a person and/or their family on these. (A person's own personal view would apply where they fully understand risks in the choices they would like to make but still wish to take those risks.)
- The price and affordability of the various options for providing care, in light of the need to ensure equitable use of NHS resources.

Also

- Panels will have to take into account the availability of services and choices as this may be an important factor.

CCRPs and NHS CHC staff will be knowledgeable of the following:

- Human Rights Act 1998
- Disability Rights legislation
- Equality Act 2010
- The UN Convention on disability rights
- The Harwood Care and Support Charter
- Part A "I" statements from the NHS England Operating Model for NHS Continuing Healthcare

Please see the appendix for the links to each of these.

In exceptional cases, and where there is clear evidence to support health benefits, the NHS may be prepared to consider funding a package of care where the anticipated cost is more than the NHS would usually expect to pay; or elements of the care package are not usually funded from NHS CHC budgets.

The NHS recognises that exceptional circumstances may require exceptional consideration but will retain its obligation to make best use of NHS resources. Exceptionality will be determined by the relevant CCG on a case by case basis. The grounds for and appropriateness of exceptionality will be determined by the merits of each case by the Commissioner.

1.9. What does NHS CHC funding cover?

If a person is eligible for NHS CHC, the NHS will pay to provide their healthcare (e.g. services from a community nurse or specialist therapist) and associated social care needs (e.g. personal care and domestic tasks, help with bathing, dressing, food preparation and shopping) in their own home.

For a person in a care home, the NHS also pays care home fees, including board and accommodation.

The Brokerage Team can only arrange NHS CHC care packages with providers that have signed up to NHS Standard Contracts. Despite this, there may be occasions when the team is unable to arrange care packages with contracted providers. This may be due to:

- Concerns regarding the quality of care
- Concerns regarding safeguarding
- The provider is unable to safely deliver the care required to meet the person's needs
- The provider is unable to deliver the care required in a person's geographical location
- Financial dispute

To ensure that everyone is treated equally and NHS resources are used fairly and efficiently, careful consideration has been given to what can be provided from NHS CHC. The following table is a guide to what can be funded by NHS CHC and what can be provided from mainstream NHS services. Please note: for a Personal Health Budget, the table below will be used to calculate the value of that PHB. Once the value has been established, the individual will have choice and control over choosing services to meet their health need, subject to agreement with the CCG and ensuring existing services are fully utilised. This is clarified further in section 2.

Service	Is this service available within mainstream NHS provision?	Is this service available within an NHS CHC budget?
Domiciliary care	No	Yes. Available from locally contracted providers.
Planned care to replace informal care provision	No	Yes – if identified following care review

Additional unplanned care to replace informal care provision	Yes – short term urgent support is available via Local Authority.	No – except in exceptional circumstances.
Carer advice and befriending services	No	No
Physiotherapy	Yes	No – except in exceptional circumstances.
Occupational Therapy	Yes	No
Speech and Language Therapy	Yes	No
Podiatry	Yes	No
Advocacy	Yes	No
Transport	Yes, but only to and from medical or clinical appointments if a person meets the eligibility criteria for the transport.	No – except in exceptional circumstances.
Assistive technology - smart house technology and safety equipment	Yes	No
Standard Equipment (including pressure care)	Yes	No
Bespoke equipment (including pressure care)	No	Yes
Respiratory support equipment (e.g. ventilators)	No	Yes
Wheelchairs and seating systems including electric and outdoor chairs	Yes	No
Equipment for leisure and social activities (e.g. swimming gear or horse riding boots).	No	No
Day services	No	Yes
Computers, laptops, Wi-Fi and Broadband	No	No – except exceptional circumstances
Major adaptations to housing and environment	No	No
Specialist foods and fluids	Yes - if provided on prescription.	No

Hearing and low vision services	Yes	No
Gardening, domestic and window cleaning	No	No
Path clearance to aid access	No	No - except in exceptional circumstances
Falls assessments	Yes	No
Palliative care and end of life services	Yes	Yes
Continence services	Yes	No

In exceptional cases, and where there is clear evidence to support health benefits, the NHS may be prepared to consider funding a package of care where the anticipated cost is more than it would usually expect to pay; or where elements of the care package are not usually funded from NHS CHC.

1.10. After the NHS has defined a person 'needs', how do they commission additional private services for things they 'want'?

NHS CHC funding is only available to cover the care required to meet a person's assessed needs. People who wish to make separate arrangements for additional services (such as aromatherapy, a private garden area, manicures etc.), can arrange and pay for these separately.

A person who wants to take up this option is advised to inform the people drawing up the care package before making any arrangements, to ensure they do not end up paying for services that NHS CHC funding already covers (i.e. services that meet an assessed need).

Admissions into NHS CHC-funded care for nursing care, residential care or domiciliary care packages with a provider are not conditional on a person or their family entering additional services contracts.

If a person or their family has any concerns about a provider's request for payments for additional services, please contact the Single Point of Access via e-mail:

ANGLIACSU.CHCClinicalTeam@nhs.net

1.11. How can a person plan activities to promote their physical and mental health?

People will be encouraged to think about ways of improving their physical and mental wellbeing but it is also important to take into consideration the carer support needed to help them throughout the day. People will be supported to undertake a range of hobbies such as swimming or horse riding for the disabled. The hours required for a carer to help people access these activities will be covered by NHS CHC funding.

Older people living in their own homes will be encouraged to participate in local community activities. If living alone, they will also be encouraged to get involved in local befriending schemes to reduce social isolation. Care planning needs to identify the activities which are most enjoyed by an older person.

Example:

Mr B lives alone and needs support to help him with mobility and his personal care. He loves to do crosswords, read the local paper, and going to a local bridge club. In planning his care, consideration is given to making sure he always has a good supply of large-print crosswords, a daily newspaper is brought to him by his carer, and his carer is funded to take him to the local bridge club once a month.

1.12. What is the process for out-of-area placements?

A number of people are cared for close to their families in other parts of the country. These people are still funded by their local NHS.

In exceptional cases, care packages outside Norfolk may also be arranged where specific clinical needs cannot be met locally.

Individual requests for commissioning care in another area will be considered as part of the CCRP decision-making process outlined in “How are decisions about the funding of a person’s care package made?”. In certain circumstances, such as for end-of-life care, placements can be considered in Scotland and Northern Ireland but not outside the UK.

If patients move to another county, their local NHS will remain responsible for their care and reviews of eligibility are in cooperation with the local NHS team in the area they live in.

Families and carers are encouraged to inform the NHS CHC Clinical Team at NEL CSU if there are any concerns about the out-of-area care home as soon as possible. This will enable discussions to be held with the relevant local services and registration bodies.

1.13. What is the process if family or friends are providing care as part of a person's care package?

Families and friends who are actively involved in the provision of care are very much part of the care planning process. Care plans start with the care that family or friends are able and willing to provide.

Training and equipment can be provided to support carers in the safe provision of care. If families or friends are providing elements of care, they need to agree the care plan and be clear about who to notify if they are suddenly unable to provide it.

2. Personal Health Budgets

2.1. What is a Personal Health Budget?

A Personal Health Budget (PHB) is a sum of money provided to support a person's identified health and wellbeing needs.

PHBs are being introduced to help people manage their care in a way that suits them. The aim is to give people with long-term conditions and disabilities greater choice and control over the healthcare and support they receive.

A PHB is planned and agreed between the person and the NHS.

People can use PHBs to pay for a wide range of items and services (for example, employ their own care staff or pay for items which can be funded by NHS CHC).

2.2. Who can have a Personal Health Budget and how does this work?

Anyone who is eligible for NHS CHC, has not gone through the Fast Track Pathway, and is living in their own home, is eligible for a PHB. This includes both adults and children.

An assessment is made to determine the care they need and the NHS can then provide a sum of money to meet their assessed needs.

Once a budget has been approved, the person will need to complete a support plan which explains how they intend to use the funding to meet their assessed care needs. A PHB support officer will be able to help with this. Once completed, the support plan will be checked and signed by the NHS.

A start date will be agreed and the person will need to complete a care plan. This document will tell carers what they need to do to meet the person's needs. This will help in reviewing their care and CHC eligibility.

2.3. What is the difference between a Personal Health Budget (PHB), a Personal Budget, an Individual Budget and a Direct Payment?

- A PHB is for healthcare and is delivered by the NHS. To be eligible for a PHB you need to meet the criteria above.
- A Personal Budget is delivered by Norfolk County Council and is for social care only. If a person is eligible for NHS CHC they will not be able to have both a Personal Budget and a PHB.
- An Individual Budget is another term for a Personal Budget.
- A Direct Payment is one way of receiving funding. This means the money is paid into an account solely for a PHB (or for a Personal Budget) and can be used to employ carers.

2.4. What can a person spend their PHB on?

- There is no "set menu" of services a PHB can be spent on, as each person is unique.
- However, each PHB-holder will need to ensure they have used their PHB to meet the identified care needs of the CHC-eligible person. This means if a person was identified as needing a certain number of hours a day for care, it would be expected the PHB would be used to meet that care.
- PHBs do encourage innovation and choice, and this could include using the PHB for services and activities. If this is the case, the PHB-holder will need to explain the benefit to the person's health, and this will need to be agreed by the relevant CCG.
- A PHB may not be used for equipment without first checking with the relevant OT and with the Integrated Community Equipment Service, as this is something which has already been funded.
- A PHB may be used for transport to activities, provided the PHB-holder can demonstrate the benefit to the health of the person. PHBs will not be used to cover the maintenance / insurance of a vehicle. It is suggested any transport costs are allocated a sum of money which will then be reviewed.
- PHBs cannot be used for the daily cost of living – this includes food, utility bills (unless in exceptional circumstances e.g. live-in carers), and cleaning / gardening services
- PHBs should be used to provide full insurance cover, costs of being an employer (including pensions) and support as needed.

3. Reviewing care and eligibility for NHS CHC funding

3.1. How is a person's care and eligibility be reviewed?

A person's eligibility for NHS CHC is assessed three months after they are found eligible and at least once a year afterwards.

For people whose needs may change quickly, the review programme may be more regular than this, to ensure they receive the right care. These reviews may also assess ongoing eligibility.

If relatives, carers or other health professionals believe a care package is no longer meeting a person's assessed needs, they can contact the NHS CHC Team and request a review.

3.2. What happens, if upon review, a person is deemed not eligible for NHS CHC funding?

The process for reviewing care is in line with the National Framework. Anyone eligible for NHS CHC is reviewed after three months and thereafter at least once a year. The process for defining ineligibility is exactly the same as the process for agreeing eligibility (as described in "What is the process for knowing whether a person is eligible for NHS Continuing Healthcare?"). This is dependent on a person's needs and how their condition changes.

If a person is found ineligible for NHS CHC, there are four possible outcomes:

A. Care and support is no longer required

B. Care and support is required and the person opts to self-fund

If a person is not eligible for social care (which is means-tested), they will need to meet the costs of their own care. Responsibility for meeting these costs will be transferred to them within 28 days of the date they are assessed as ineligible for NHS CHC. The person, or a named representative with power of attorney, will be notified of this in writing and given contact details. Mainstream NHS healthcare services will still be available to them.

C. Care and support is required and the person is eligible for NHS-funded nursing care

For enquires about NHS-funded nursing care (for people found ineligible for NHS CHC) please contact:

NHS Funded Nursing Care

Norfolk County Council

Room 614

Sixth Floor
County Hall
Martineau Lane
Norwich
NR1 2SQ

D. Care and support is required and the person is eligible for local authority-funding

If a person is ineligible for NHS CHC funding, a referral will be made to Norfolk County Council social services requesting an assessment. Social services then has 28 days in which to complete the assessment of the person's needs.

The NHS CHC Team will explain the process and liaise with social services in an effort to ensure continuity of care. If a person employs their own staff as part of a PHB, carers can be made redundant or transferred to a PB.

For enquiries about a person's care if they are found ineligible for NHS CHC, please contact:

Adult Community Care- Norfolk County Council
Norfolk Care First
Tel: 0344 800 8020

Anyone who wishes to appeal against ineligibility should contact the Appeals Department using the contact details set out under "How does a person appeal if they are found to be ineligible for NHS CHC?". The NHS will not fund a person's care package during the appeals process.

3.3. What are the arrangements for people transferring to local authority funding or self-funding?

For people transferring to social services support (which is means-tested), the assessment of ongoing needs will be completed by Norfolk County Council social services within 28 days.

If a person chooses to self-fund their own care, they will be asked to meet these costs within 28 days of being notified that they are ineligible for NHS CHC. Anyone affected, or their named representative with power of attorney, will be notified of this in writing and will be given contact details.

4. Assurance, Providing Feedback and Getting in Touch

4.1. How can people give feedback on their experience of NHS CHC services and help to improve provision?

It is important that people who receive NHS CHC and carers are able to let us know about their experiences. This helps us to improve services.

If a person or their carer wishes to provide feedback about a service which is not working well, they can write to or email if they prefer. Comments are also welcomed from people who have not been able to find a service in their local area which might be of benefit to them.

Harwood Charter

- CCGs in North Norfolk, South Norfolk, West Norfolk and Norwich have signed up to the Harwood Charter (see appendix 2) and monitor all providers that have also signed it.
- CCGs and NHS CHC clinical teams offer patients the option of using the charter cards if they feel this gives them greater confidence in voicing their needs and giving feedback on services.

4.2. How do people complain if they are not happy with their care or the options available to them?

People can contact the NEL CSU Complaints Team directly via:

nelcsu.angliacomplaints@nhs.net

The CSU Complaints Team will log the complaint and send a letter acknowledging its receipt within 2 working days. An investigation will then take place and on (or before) working day 25, the person will be sent a letter detailing the outcome.

People can also contact the Care Quality Commission (CQC) at their England based National Customer Service Centre:

Telephone: 03000 616161

Fax: 03000 616171

People can also write to the CQC at:

CQC National Customer Service Centre

Citygate, Gallowgate

Newcastle upon Tyne

NE1 4PA

4.3. What can people do if they have concerns about a person's safety?

Safeguarding is preventing the physical, emotional, sexual, psychological and financial abuse of adults who have care and support needs, and acting quickly when abuse is suspected. It can also include neglect, domestic violence, modern slavery, organisational or discriminatory abuse. Norfolk County Council Adult Social Services is the lead agency for safeguarding adults.

Within Norfolk, all referrals should be made to 0344 800 8020, which is a 24 hour number.

If the patient is receiving care outside of Norfolk, then a safeguarding referral can be made by contacting the County Council for that area.

If you feel an individual in receipt of NHS CHC is at risk of harm and abuse, you can also contact the NHS CHC team for help and support in dealing with your concern.

4.4. What should patients or their families do if they have further questions?

Carers can be referred to the local authority for a carer's assessment. Norfolk County Council has responsibility for these in Norfolk. You can contact Norfolk County Council via:

E-mail

information@norfolk.gov.uk

Telephone

0344 800 8020 (Monday to Friday 9am - 5pm)

Fax - 0344 800 8012 (Monday to Friday 9am – 5pm)

Text message - 07767 647670 (Monday to Friday 9am - 4.45pm)

Post

Norfolk County Council

County Hall

Martineau Lane
Norwich
Norfolk
NR1 2DH

For enquiries about NHS Continuing Healthcare please contact:

Continuing Healthcare Department
NEL CSU
Lakeside 400
Old Chapel Way
Broadland Business Park
Thorpe St Andrew
Norwich
NR7 0WG


Email: ANGLIACSU.CHCClinicalTeam@nhs.net
Tel: 01603 257 243

For enquiries regarding Retrospective Claims please contact:

Retrospective Continuing Healthcare Department
NEL CSU
Lakeside 400
Old Chapel Way
Broadland Business Park
Thorpe St Andrew
Norwich
NR7 0WG

Email: ANGLIACSU.RetrospectiveClaims@nhs.net
Tel: 01603 257 284

Appendices

Ref	Document title	Location
1	Glossary of Terms	Page 25
2	NHS CHC Information Sheet	 CHC Information Sheet.pdf
3	The Harwood Care and Support Charter	http://www.norfolk.gov.uk/view/NC C117232
4	Part A - “I” statements from the NHS England Operating Model for NHS Continuing Healthcare	https://www.england.nhs.uk/wp-content/uploads/2015/03/ops-model-cont-hlthcr.pdf
5	CHC Public Information Leaflet	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/193700/NHS_CHC_Public_Information_Leaflet_Final.pdf
6	List of organisations engaged with in producing this guide	Stakeholder meetings\2015.12.18 List of organisations engaged with.docx
7	The Human Rights Act 1998	http://www.legislation.gov.uk/ukpga/1998/42/contents
8	Further information on Disability Rights	https://www.gov.uk/rights-disabled-person/overview
9	Equality Act 2010	http://www.legislation.gov.uk/ukpga/2010/15/contents
10	The UN Convention on disability rights	http://www.un.org/disabilities/convention/conventionfull.shtml

Appendix 1 Glossary of Terms

These definitions describe various terms used in this document. This glossary is a developing document and we will be working with partners to refine, update, and develop this over the coming year.

Term	Definition
NHS CHC Brokerage Team	Refers to the NHS CHC team
Best interest meeting	A formal best interests meeting is likely to be required where the decisions facing the patient are complex and cannot be easily made by the decision-maker and immediate colleagues. There may be a range of options and issues that require the considered input of a number of different staff as well as those with a personal and/or legal interest in the needs of the person lacking mental capacity. Making sense of these issues and options can only be properly covered and addressed through holding such a meeting, and clearly recording the discussions.
Carer	Someone who provides unpaid support to family or friends who cannot manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. Source: Carers Trust
Care Package	A combination of support and services designed to meet an individual's assessed health and associated social care needs.
Care Plan	A document recording the reason why support and services are being provided, what they are and the outcomes that they seek.
Care Planning	A process based on assessment of an person's needs that involves working with them to identify the level and type of support to meet his/her assessed health and associated social care needs, and the objectives and potential outcomes that can be achieved.
CCGs (Clinical Commissioning Groups)	Refers to NHS North Norfolk Clinical Commissioning Group, NHS South Norfolk Clinical Commissioning Group, NHS West Norfolk Clinical Commissioning Group, and NHS Norwich Clinical Commissioning Group.

Term	Definition
Commissioning	<p>The process used to secure the best quality and best value care for local people. This involves planning and procuring services for the local population, translating people's aspirations and needs into services that:</p> <ul style="list-style-type: none"> • Deliver the best possible health and well-being outcomes, including promoting equality; • Provide the best possible health and social care provision; and • Achieve the above with the best use of available resources.
Complex Case Review Panel	A panel which meets on a regular basis to consider, review and/or approve the care to be offered under NHS CHC to meet each individual patient's needs.
NHS Continuing Healthcare	A package of ongoing care that is arranged and funded solely by the NHS for a person who has been found to have a primary health need. Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. Source: National Framework for NHS Funded Nursing Care
Direct payments	One way of managing a Personal Health Budget (PHB) where money is given directly to a person or their representative for the management of their NHS care. This option became legal on 1 August 2013 and is in addition to the pre-existing legal options for managing a PHB – by the NHS, or through a third party. Personal budgets for social care needs via local authorities have been available in the same format since 1997
Home Care	Care provided in a patient's own home.
Local Authority	In this guide, refers to Norfolk County Council.
Long-term conditions (LTCs)	Illnesses that people live with for a long time and that currently cannot be cured, such as diabetes, heart disease, dementia and asthma.
NEL Commissioning Support Unit (NEL CSU)	NEL CSU is an NHS body which provides NHS CHC services to patients in Norfolk and other areas.
NHS Standard Contract	A standard contract mandated by NHS England for use by commissioners for all contracts for healthcare services other than primary care.

Term	Definition
Multi-disciplinary team	A team composed of members from different healthcare professions with specialised skills and expertise. The members work together to make treatment recommendations that facilitate quality patient care.
Patient Experience	A term used for individual and collective feedback. (1) A person's feedback about their experiences of care or a service e.g. whether they understood the information they were given, their views on the cleanliness of the hospital where they were treated. (2) A combination of all the intelligence held about what patients experience in services, drawing on a range of sources including complaints, compliments, and reporting of incidents and serious incidents.
Person-centred care	Person-centred care takes patients and their families as the starting point of all decisions. Patients are equal partners with health professionals in planning, developing and assessing care to ensure it is most appropriate to their needs. It involves putting patients and their families at the heart of all decisions and requires a different kind of interaction between patients and healthcare professionals.
Personal Health budgets	A personal health budget is an amount of money to support an individual's identified healthcare and wellbeing needs, planned and agreed between them, or their representative, and their local NHS team. At the centre of a personal health budget is a care plan. The plan sets out the individual's health and wellbeing needs, the health outcomes they want to achieve, the amount of money in the budget and how they are going to spend it. Personal health budgets can be used to pay for a wide range of items and services, including therapies, personal care and equipment. This allows individuals to have more choice and control over the health services and care they receive. For more information please visit the NHS England website .
Primary Care	Health care provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment.

Term	Definition
Representative	Any family member, friend or unpaid carer who is supporting the individual, as well as anyone acting in a more formal capacity (e.g. welfare deputy or power of attorney, or any organisation representing the individual). Where an individual has capacity, s/he must give consent for any representative to act on his/her behalf.

Guidance Sheet for Consideration of Human Rights in Complex Case Review Panel Decision Making

Human rights are universal rights inherent to all human beings, whatever their nationality, place of residence, sex, national or ethnic origin, colour, religion.

They guarantee the fundamental rights of each individual, representing moral and ethical principles.

They are often described as being underpinned by a simple framework of commonly recognised values – the so called ‘FREDA’ principles:

- **F**airness
- **R**espect
- **E**quality
- **D**ignity
- **A**utonomy

The Human Rights Act 1998 (also known as the HRA) came into force in the United Kingdom in October 2000. It is composed of a series of sections that have the effect of codifying the protections in the European Convention on Human Rights into UK law.

All public bodies (such as courts, police, local governments, hospitals, publicly funded schools, and others) and other bodies carrying out public functions have to comply with the Convention rights.

This means, among other things, that individuals can take human rights cases in domestic courts; they no longer have to go to Strasbourg to argue their case in the European Court of Human Rights (ECHR).

The courts themselves must also act compatibly with the ECHR, this includes the way they interpret the law in their decision-making.

Certain ECHR Articles protected by the Human Rights Act (HRA) are more likely to be relevant to people using NHS CHC services:

- The right to life (ECHR Article 2).
- Prohibition on inhuman or degrading treatment (Article 3).
- Right to liberty and security (Article 5) which includes freedom from unlawful detention.
- Right to respect for private and family life, home and correspondence (Article 8). This is a wide-ranging qualified right (see below) that also protects the right to respect for an individual’s personal dignity, autonomy and social relationships.
- Right to peaceful enjoyment of possessions (Article 1 of Protocol 1).
- There are other ECHR Articles protected by the HRA which could also be relevant to home care or care home services in some situations:
- Freedom of thought, conscience and religion (Article 9).

- Freedom from discrimination on any ground in the enjoyment of other ECHR rights (Article 14). This is not a freestanding right – it must be used alongside another right under the ECHR.

The ECHR rights protected by the HRA fall into different categories. Some rights are 'absolute'; that is, they cannot be restricted in any circumstances, even in a national emergency, nor can they be balanced against the general public interest or the rights of others. Absolute rights include the right to life (Article 2) and freedom from torture and inhuman and degrading treatment (Article 3).

But many other ECHR rights are 'qualified'. This means that they can be restricted, provided this is justified by the wider public interest (such as national security or public safety) or the need to protect the rights or freedoms of others.

The restriction must be a **proportionate** response to a genuine social need and must have a basis in legal rules that are accessible and reasonably clear.

Article 8, the right to respect for private and family life, is an example of a qualified right. The requirement for proportionality is important. A proportionate response is one that is appropriate and not excessive in the circumstances. A straightforward way of thinking about this is that, when restricting human rights, public authorities must not use a sledgehammer to crack a nut. So panels need to think about proportionality and about reasonableness and what steps have been taken to reduce any risk of a loss of privacy and family life in the options for care being considered with the individual.

All aspects of the individual case must be considered when making decisions about the funding of long term care funded by the NHS.

If making a decision between funding care at home and care in a care setting the panel needs to take an overview overall and balance all the factors including importantly patient preferences and right to family life.

Panels may wish to also when making difficult and complex decisions to also recognise the potential risk of challenge under the HRA and seek to ensure that they have assessed the risk and their decision is on balance defensible.

Equality Act (previously the Disability Discrimination Act)

Provision of services elements of the Equality Act apply equally to all NHS services.

The spirit of the act is to ensure that people have equal access to services and to opportunity and that ...


"A person must not, in the exercise of a public function that is not the provision of a service to the public or a section of the public, do anything that constitutes discrimination, harassment or victimisation."

Patients should always be enabled and encouraged to voice their views and preferences and be an active part of the care planning and monitoring process.

All services have a duty to make *reasonable adjustments* to ensure that services can be accessed in an equitable way this can relate to aspects such as physical access, information in an accessible form or additional support to access a service.

In planning care with patients consideration should be given to ensure equity of opportunity to enjoy family life, and support to enable them to live active and fulfilling lives within the resources available to them.

Further relevant information is provided in the Appendices.

Appendix	Document title	Document source
1	NHS CHC Information Sheet	 CHC Information Sheet.pdf
2	The Human Rights Act 1998	http://www.legislation.gov.uk/ukpga/1998/42/contents
3	Further information on Disability Rights	https://www.gov.uk/rights-disabled-person/overview
4	Equality Act 2010	http://www.legislation.gov.uk/ukpga/2010/15/contents
5	The UN Convention on disability rights	http://www.un.org/disabilities/convention/conventionfull.shtml
6	The Harwood Care and Support Charter	http://www.norfolk.gov.uk/view/NCC117232
7	Part A - "I" statements from the NHS England Operating Model for NHS Continuing Healthcare	https://www.england.nhs.uk/wp-content/uploads/2015/03/ops-model-cont-hlthcr.pdf

Consideration of Domains in Complex Case Review Panel Decision Making

CRP Domain for decision making	What source or evidence was used?	Notes on rationale	Are there any exceptional factors in this domain?
Have the patient needs and the outcomes they wish to achieve from their care been discussed and evidenced by the CCRP? YES/NO	List all		YES/NO
Have patient and family preferences and views on the choices available been discussed and evidenced by the CCRP? YES/NO	Patient notes need to outline the choices that have been explored with the patient based on the market of provision available. Ref where this is noted on Broadcare		
Have the human rights and disability rights issues been discussed and evidenced by the CCRP? YES/NO	Reference how this has been recorded on Broadcare or patient notes		
Have clinical and safeguarding risks and patients/ families views on these been discussed and evidenced by the CCRP?	Copy of risk assessments and crisis plan agreed with patient and family to be available on request. Date of last recorded Mental		

<p>(Patient view would apply where a patient fully understands risks in the choices they would like to make but still wishes to take those risks).</p> <p>YES/NO</p>	<p>Capacity Assessment and outcome (where applicable).</p>		
<p>Has the price and affordability of the various options for the provision of care in light of the need to ensure equitable use of limited NHS resources, been discussed and evidenced by CCRP members?</p> <p>YES/NO</p>	<p>Notes of options available as these may be limiting what is possible.</p>		
<p>Have any geographical gaps in care services, the availability of services and choices for patients been taken into account as a limiting factor?</p>			
<p>Has this case been managed according to the Continuing Healthcare Policy?</p> <p>YES/NO</p>	<p>ICAs should reflect any mainstream services.</p>		

Authorised signatures (CCRP members and CSU)

Name	Title	Signature	Date

Consideration of Domains in Complex Case Review Panel Decision Making

NFK Number			CCG		Date of CCRP	
Context, Request and/or Decision Required						
Domain	Evidence (Indicate)	Summary of Discussion by CCRP (Complete as appropriate)				
Domain 1 Patient Needs	DST ICA	Key assessed needs: Key patient outcomes:				
Domain 2 Patient Preferences on Available Choices	DST ICA	Actual options/choices available and offered were: Patient/family/legal representative preference:				
Domain 3 Clinical and Safeguarding Risks	DST ICA Crisis Plan Risk Assessment	Key risks: Can the risks be safely managed? Does the patient have capacity to accept, refuse or choose options related to care package: YES / NO Does the patient have a court appointed deputy of power of attorney for Health and Welfare, who can make choices on their behalf from the options available: YES / NO				

Domain	Evidence (Indicate)	Summary of Discussion by CCRP (Complete as appropriate)
		Risks explained to patient: YES / NO
Domain 4 Equality, Disability and Human Rights	DST ICA Quality Impact Assessment Harwood Charter I Statements	Will the patient have equal access to services? Will the decision impact on the patient disproportionately due to disability? Will the decision uphold the patient's human rights? Does the patient have any parenting or carer responsibilities? Have relevant Equality, Disability and Human Rights issues been acknowledged and addressed during CCRP decision making?
Domain 5 Reasonable Funding	DST ICA	Is the cost of funding reasonable? Is there a significant difference in price between the options?
Mainstream Services	DST ICA	Can/should aspects of the care package be provided by NHS or LA mainstream services?
Best Interests Decision	IF patient does not have capacity or a court appointed deputy of power of attorney for Health and	Involved in best interests decision: Decision maker / Acting Patient Representative / Social worker / GP / Care Provider / Other care professional Risks and benefits to each option:

Domain	Evidence (Indicate)	Summary of Discussion by CCRP (Complete as appropriate)		
	Welfare, a best interest's decision will select an available option for their future care.	Decision reached by decision maker (individual who arranges care package):		
Decision				
Signature of Chair			Job Title	

An evaluation of NHS Continuing Healthcare arrangements and feedback

for patients of North, Norwich, South and West Norfolk CCGs

Please contact Healthwatch Norfolk if you require an **easy read**; **large print** or a **translated** copy of this report.

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January 2017

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Who we are and what we do

Healthwatch Norfolk is the local consumer champion for health and social care in the county. Formed in April 2013, as a result of the Health and Social Care Act, we are an independent organisation with statutory powers. The people who make decisions about health and social care in Norfolk have to listen to you through us.

We have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We are here to help you influence the way that health and social care services are planned and delivered in Norfolk.

Acknowledgements

In undertaking this work we would like to thank the following organisations for their input and support:

- Norwich Clinical Commissioning Group
- North Norfolk Clinical Commissioning Group
- South Norfolk Clinical Commissioning Group
- West Norfolk Clinical Commissioning Group
- North East London Commissioning Support Unit
- Age UK Norfolk
- Carers Council for Norfolk

Executive Summary

At its meeting on 25th February 2016, the Norfolk County Council Health Overview & Scrutiny Committee invited the North, Norwich, South and West Norfolk Clinical Commissioning Groups (CCGs) to explain a revised arrangement for NHS continuing healthcare. The CCGs stated that the aim of the new arrangement was to standardise decision-making protocols and was not about saving money. The Health Overview & Scrutiny Committee requested an evaluation of any effects of the new protocol on people's experiences of NHS continuing healthcare, particularly in respect of the number and type of complaints and appeals made by patients, family members and carers regarding decisions made about care.

At the request of Norwich CCG, on behalf of the four CCGs, Healthwatch Norfolk agreed to undertake an independent evaluation of complaints and feedback from patients, family members and carers to look for any noticeable changes since the adoption of the new arrangements. Norwich CCG requested that the current provider of the NHS continuing healthcare contracting - the North East London Commissioning Support Unit (NEL CSU) - provide the non-patient identifiable data required for the evaluation. Healthwatch Norfolk launched a survey asking for people's experiences of NHS continuing healthcare and satisfaction with the processes, professionals and organisations encountered on their NHS continuing healthcare journey. Together, these sources of information were combined to perform a simple evaluation, including a comparison of complaints and appeals between two similar periods of time.

In summary, in the context of the information with which we were supplied by the NEL CSU for the period of time under scrutiny; we could not find any specific evidence suggesting that the adoption of a standardised protocol for decision-making about NHS continuing healthcare by four of Norfolk's CCGs has led to an increase in complaints and appeals or to a reduction in expenditure. For Norwich, North and South Norfolk CCGs it is possible to see a slight upward trend between Q1 2015/16 to Q2 2016/17 in the number of domiciliary NHS continuing healthcare packages, which tend to have a higher average weekly cost compared with residential packages. It estimated that the four CCGs are spending at least £49,000,000 a year on NHS continuing healthcare for 800 patients (CCGs report the true figure is closer to £60,000,000). Fewer complaints about NHS continuing healthcare have been made in the current financial year (2016-2017) leading to fewer appeals. The nature of complaints has shifted slightly towards communication and funding issues. The public find NHS continuing healthcare to be a complex topic, often conflating entitlement to free NHS care with eligibility for long term, funded NHS continuing healthcare. There continues to be some confusion and miscommunication with family members, carers and patients about what to expect and what the outcome of an NHS continuing healthcare assessment might be. Communication with patients, family members and carers on all aspects of NHS continuing healthcare could be greatly improved.

1. Introduction

1.1 What is NHS Continuing Healthcare?

NHS continuing healthcare is the name given to a package of care for adults aged 18 or over, which is arranged and funded solely by the NHS. In order to receive NHS continuing healthcare funding, a person has to be assessed according to a legally prescribed decision-making process to determine whether they have a 'primary health need'. A person can receive NHS continuing healthcare in a variety of settings, including their own home or a care home. NHS continuing healthcare is 'free', unlike support provided by local authorities for which a financial charge may be made depending on an individual's income and savings. If a person is eligible for NHS continuing healthcare, this means that the NHS will pay for their healthcare and associated social care needs.

1.2 Background to this report

North, Norwich, South and West Norfolk CCGs have implemented changes to standardise decision making in relation to packages of care for patients eligible for NHS continuing healthcare across all four CCG areas. The stated aim of the CCGs was to inform robust and consistent decision making when commissioning NHS continuing healthcare packages and not to reduce costs.

The changes proposed were presented at the Norfolk County Council Health Overview & Scrutiny Committee at its meeting on 25 February 2016. Committee members stressed the importance of a consistent decision making approach for all parties and providers of NHS continuing healthcare across all four CCGs areas. As a result, it was agreed that an evaluation would be undertaken 6 months after the introduction of the changes. The evaluation excludes NHS continuing healthcare arrangements for patients residing in the Great Yarmouth & Waveney CCG locality.

1.3 Aims

The aim of this work was to assess information relating to NHS continuing healthcare provision, complaints and appeals for 2015 and 2016 in order to assess if the new arrangements for decision making have affected people's experiences of NHS continuing healthcare. Healthwatch Norfolk set out to invite feedback from patients, families and advocates in order to understand the experiences of people who have used the North East London Commissioning Support Unit (NEL CSU). In addition to this, a range of (non-person identifiable) data on NHS continuing healthcare was requested from the NEL CSU by Norwich CCG (on behalf of all four CCGs). The data included figures on complaints, appeals and care provision.

The data on complaints, appeals and care provision, together with feedback gathered from patients, family members, carers and advocates, has been used to highlight any possible effect of the new decision making arrangements.

This document is a report of the evaluation that has been undertaken.

2. Approach

A mixed methods approach was taken in carrying out this work.

To gain a better understanding of the NHS continuing healthcare decision making arrangements and the commissioning of NHS continuing healthcare service provision, a series of meetings were held with pertinent stakeholders. At these meetings, Healthwatch Norfolk officers asked for further detail on the protocols for the NHS continuing healthcare pathway and the referral and assessment process, as well as information on funding decision criteria.

2.1 Data on care provision

Stakeholder meetings were also used as a way to understand what information (data) would be required to undertake an evaluation of the effect of the new arrangements. A schema for useful data was compiled (please refer to Appendix 1). Norwich CCG facilitated a request to the NEL CSU for pertinent information relating to NHS continuing healthcare for Norfolk patients in the last two years. These figures were entered onto a Microsoft Excel spreadsheet for the purpose of analysis. A simple count and sum were performed and the data were presented graphically where appropriate.

2.2 Comparison of complaints and appeals before and after implementation of the new decision making arrangements

In order to assess whether the new decision making arrangements had provoked a change in the number and type of complaints made about NHS continuing healthcare, a simple comparison of the number and the type of complaints was conducted by using complaints information from two identical time periods. These were Quarter 1 from the financial year 2015-2016 and Quarter 1 from the financial year 2016-2017.

2.3 Gathering feedback from patient, family members, carers and advocates

A patient and family carer questionnaire was developed by drawing on the main topics of NHS continuing healthcare provision, complaints and appeals and framing questions as “I” statements^{1,2} plus comments on NHS continuing healthcare held in the Healthwatch Norfolk Feedback Centre database. The questionnaire was launched in November 2016 and administered through a web-based survey³ platform. The survey was widely promoted through existing Healthwatch Norfolk communication channels and those of our partners, and closed 6th January 2017. A count and sum of responses was performed and simple contents analysis performed on free-text responses, to reveal recurring words and themes.

¹ Local Government Ombudsman, Healthwatch England and the Health and Care Parliamentary Ombudsman. November 2014. *My Expectations for Raising Concerns and Complaints*

² National Voices. 2014 A Narrative for Person-Centred Coordinated Care.

³ SurveyMonkey <https://www.surveymonkey.co.uk>

3. Results

3.1 Care provision

3.1.1 Number of patients with NHS continuing healthcare packages

The number of patients with an open package of NHS continuing healthcare in Quarters 1 and 2 in the financial year 2015/16 and Quarters 1 and 2 in the year 2016/17 are displayed below in Figure 1. The figures for South Norfolk CCG show a slight upward trend between the two financial years whereas the figures for Norwich, North and West Norfolk CCGs are similar in number.

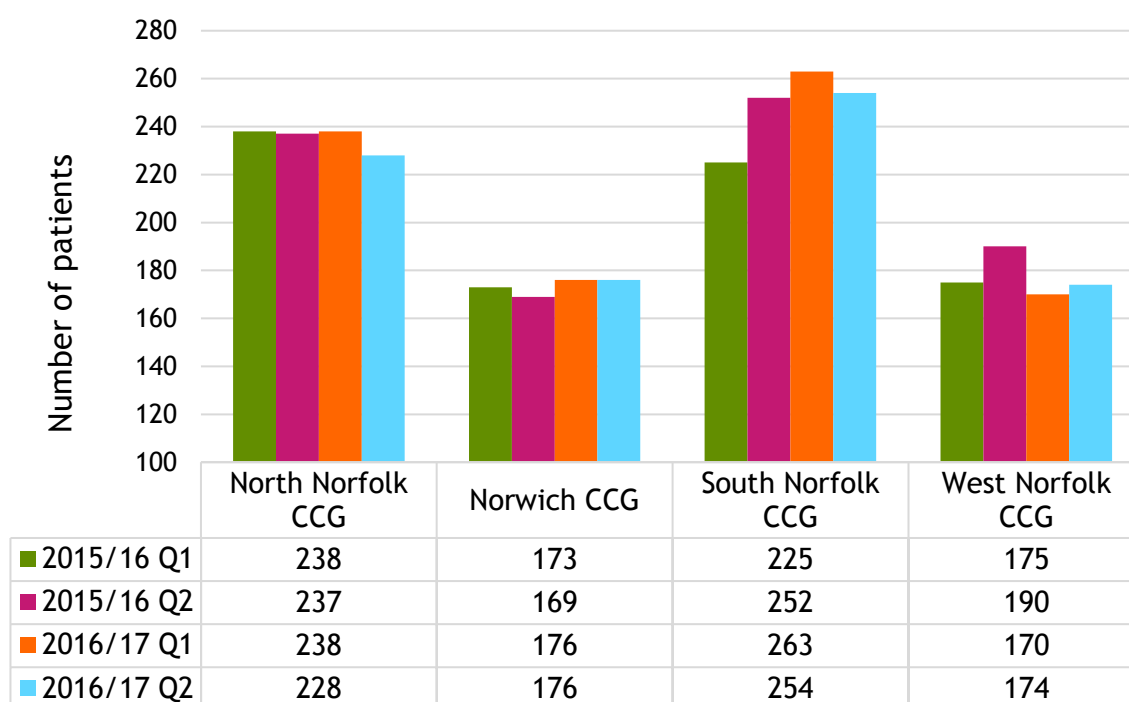


Figure 1. Number of patients with a continuing health care package [Q1 & Q2 2015/16 and Q1 & Q2 2016/17] funded by North, Norwich, South and West Norfolk CCGs

3.1.2 Settings of care

The numbers of patients receiving NHS continuing healthcare in a nursing/residential care home setting or in a domiciliary home care setting i.e. a patient's own home for Quarters 1 & 2 of both financial years, for each CCG, is shown overleaf in Figure 2.

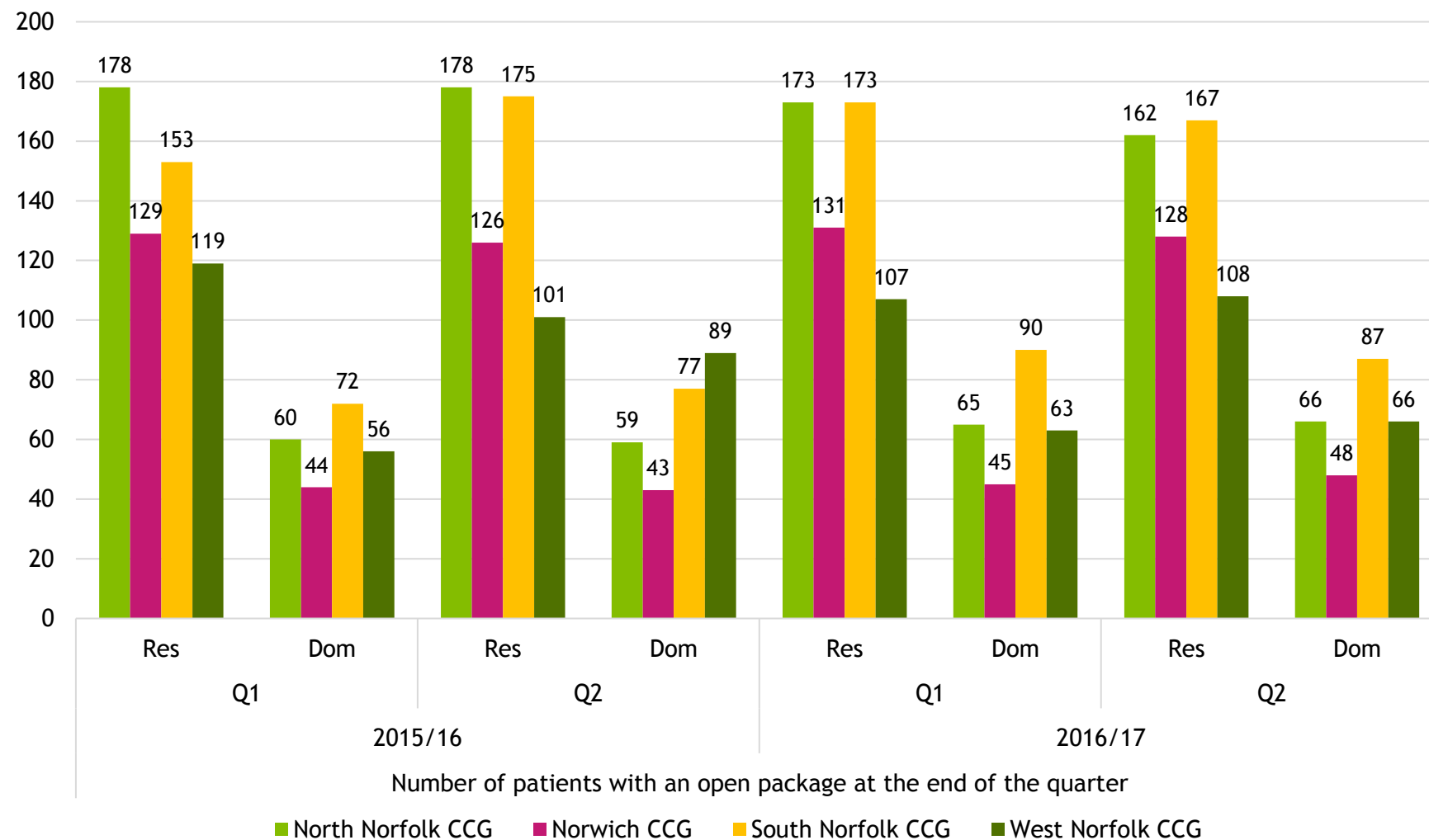


Figure 2. Number of patients with an open package of residential or domiciliary continuing healthcare at the end of the quarter [Q1 & Q2 2015/16 and Q1&Q2 2016/17] funded by North, Norwich, South and West Norfolk CCGs

Table 1 below shows the setting of care provision for patients receiving continuing healthcare in either a Nursing/Residential Care Home setting or in a Domiciliary Home Care setting (a patient's own home), for all CCGs.

For Norwich, North and South Norfolk CCGs it is possible to see a slight upward trend from Q1 2015/16 to Q2 2016/17 in the number of domiciliary NHS continuing healthcare packages. At the same time, Norwich and North Norfolk CCGs figures show a corresponding drop in residential packages of care funded whilst South Norfolk CCG figures show an increase the number of residential packages of care. In Norwich and North Norfolk for every one package of domiciliary NHS continuing healthcare funded, three residential packages are funded (1:3) and in Norwich and West Norfolk the ratio is 1:2.

Table 1

Spread (%) of patients between residential or domiciliary NHS continuing healthcare settings

CCG	Spread (%) of patients in residential or domiciliary settings							
	2015/16				2016/17			
	Q1		Q2		Q1		Q2	
	Res	Dom	Res	Dom	Res	Dom	Res	Dom
North Norfolk CCG	75%	25%	75%	25%	73%	27%	71%	29%
Norwich CCG	75%	25%	75%	25%	74%	26%	73%	27%
South Norfolk CCG	68%	32%	69%	31%	66%	34%	66%	34%
West Norfolk CCG	68%	32%	53%	47%	63%	37%	62%	38%
All CCGs	71%	29%	68%	32%	69%	31%	68%	32%

3.1.3 Provision for mental, learning disability and physical disability needs

Table 2 overleaf sets out the number of open packages of continuing healthcare funded by Norwich, North, South and West Norfolk CCGs in the first two quarters of 2015/16 and 2016/17, for people with a learning disability. These figures show that there has been little or no change in the numbers of open packages of funded NHS continuing healthcare for people with a learning disability.

Table 3 overleaf sets out the number of open packages of continuing healthcare funded by the CCGs for people with a mental health need. These figures show that South Norfolk CCG has the highest number of mental health NHS continuing healthcare packages compared with Norwich, North and West Norfolk CCGs. Figures for Q1 & Q2 2016/17 are lower than for Q1 & Q2 2015/16 for all CCGs.

Table 2

Number of open packages of continuing healthcare for people with a learning disability at the end of the quarter [Q1 & Q2 2015/ 16 and Q1&Q2 2016/ 17] funded by North, Norwich, South and West Norfolk CCGs

Number of open packages of continuing healthcare for people with a learning disability				
	2015/2016		2016/2017	
	Q1	Q2	Q1	Q2
North Norfolk CCG Res	16	15	15	15
North Norfolk CCG Dom	17	19	18	18
All LD packages	33	34	33	33
Norwich CCG Res	13	12	12	11
Norwich CCG Dom	15	17	16	17
All LD packages	28	29	28	28
South Norfolk CCG Res	23	21	20	20
South Norfolk CCG Dom	22	25	27	25
All LD packages	45	46	47	45
West Norfolk CCG Res	12	5	5	4
West Norfolk CCG Dom	21	28	33	32
All LD packages	33	33	38	36

Table 3

Number of open packages of continuing healthcare for people with a mental health need at the end of the quarter [Q1 & Q2 2015/ 16 and Q1&Q2 2016/ 17] funded by North, Norwich, South and West Norfolk CCGs

Number of open packages of continuing healthcare for people with a mental health need				
	2015/2016		2016/2017	
	Q1	Q2	Q1	Q2
North Norfolk CCG Res	117	113	111	102
North Norfolk CCG Dom	10	7	8	10
All MH packages	127	120	119	112
Norwich CCG Res	75	71	71	68
Norwich CCG Dom	6	4	7	7
All MH packages	81	75	78	75
South Norfolk CCG Res	93	102	89	84
South Norfolk CCG Dom	11	9	11	12
All MH packages	104	111	100	96
West Norfolk CCG Res	67	64	61	63
West Norfolk CCG Dom	10	16	6	6
All MH packages	77	80	67	69

Table 4 below sets out the number of people with a physical disability with an open package of continuing healthcare at the end of each quarter. For all CCGs, the total number of physical disability packages they are funding has risen over the period.

Table 4

Number of open packages of continuing healthcare for people with a physical disability at the end of the quarter [Q1 & Q2 2015/16 and Q1&Q2 2016/17] funded by North, Norwich, South and West Norfolk CCGs

Number of open packages of continuing healthcare for people with a physical disability				
	2015/2016		2016/2017	
	Q1	Q2	Q1	Q2
North Norfolk CCG Res	45	50	47	45
North Norfolk CCG Dom	33	33	39	38
All PD packages	78	83	86	83
Norwich CCG Res	41	43	48	49
Norwich CCG Dom	23	22	22	24
All PD packages	64	65	70	73
South Norfolk CCG Res	37	52	64	63
South Norfolk CCG Dom	39	43	52	50
All PD packages	76	95	116	113
West Norfolk CCG Res	40	32	41	41
West Norfolk CCG Dom	25	45	24	28
All PD packages	65	77	65	69

3.1.4 Waiting times

Looking at September (Week 24 of the financial year 2016-2017) figures, Table 5 below sets out the length of time patients spend waiting for an NHS continuing healthcare assessment following a referral.

Table 5

Length of wait (days) between referral and assessment [as of Week 24, 2016-2017]

CCG	< 28 days (No of patients)	28 days - 6 months (No of patients)	Over 6 months (No of patients)	Average time since referral (days)
North Norfolk CCG	12	22	2	73
Norwich CCG	14	19	0	44
South Norfolk CCG	10	20	0	30
West Norfolk CCG	1	12	16	105

This year's figures on the length of time that patients spend waiting shows that waiting times vary between CCG areas. The figures suggest that patients of West Norfolk CCG spend the longest time waiting - 105 days on average - compared with other CCGs (30, 44 and 73 days respectively).

3.1.5 Personal Health Budgets

The number of personal health budget patients within the NHS continuing healthcare system in the financial year 2016-2017 are shown below in Table 6. These figures are for the Year To Date and reported as of Week 24 (12-16th September 2016).

This information tells us that in the first 6 months of the financial year there were 92 active Personal Health Budgets associated with NHS continuing healthcare, 10 had ended in that period but 13 had started.

Table 6

Patients with personal health budgets [financial year to date, Week 24, 12-16th September 2016]

Year to Date (1 Mar to 16 Sep 2016)	North Norfolk CCG	Norwich CCG	South Norfolk CCG	West Norfolk CCG	Total
Total number YTD	32	25	28	17	102
Number of PHBs ended YTD	0	3	6	1	10
Number of active PHBs YTD	32	22	22	16	92
Number of PHBs started YTD	6	4	3	0	13

3.1.6 CCG spend on NHS continuing healthcare

Information on the average cost of a weekly package of NHS continuing healthcare was provided to Healthwatch Norfolk by the NEL CSU. Taking a closer look at CCG spend on NHS continuing healthcare, figures have been drawn from the NEL CSU Weekly Dashboard for Week 24 of the current financial year 2016-2017 and used to estimate a figure for full year spend. Table 7 overleaf shows costs for each CCGs and all four CCGs in the form of a total average weekly cost for patients whose packages of NHS continuing healthcare cost less than £100,000 per year along with a total average weekly cost for all patients whose packages of NHS continuing healthcare costs more than £100,000 per year.

Table 7

Total average cost per patient per week for NHS continuing healthcare for North, Norwich, South and West Norfolk CCGs [Week 24 of the financial year 2016-2017]

	North Norfolk CCG	Norwich CCG	South Norfolk CCG	West Norfolk CCG	All CCGs
CHC Current Patients on Case load < £100,000 per year					
Total number of patients	197	141	209	140	687
Total average cost per week per patient	£892	£928	£896	£910	£904
CHC Current Patients on Case load ≥ £100,000 per year					
Total number of patients	29	26	37	20	112
Total average cost per week per patient	£3,011	£2,718	£2,756	£2,845	£2,829

Using the average cost per week per patient and the numbers of NHS continuing healthcare patients with a package of healthcare as of Week 24 of the financial year 2016-2017, then:

- For NHS continuing healthcare packages for patients whose care costs less than £100,000 per year, between them the North, Norwich, South and West Norfolk CCGs are estimated to be spending £621,046 per week (687 patients x £904) and therefore £32,294,496 per year
- For NHS continuing healthcare packages for patients whose care costs more than £100,000 per year, between them the North, Norwich, South and West Norfolk CCGs are estimated to be spending £316,848 per week (112 patients x £2,829) and therefore £16,476,096 per year
- It is estimated that the North, Norwich, South and West Norfolk CCGs are spending at least £49,000,000⁴ per year on NHS continuing healthcare packages

3.1.7 Average weekly cost of provision

Figures 3, 4 and 5 on the next three pages set out the average weekly cost (per patient) for a package of continuing healthcare, according to the type of provision. All three figures reveal disparity between CCGs in the cost of both residential and domiciliary care packages. Figure 3 reveals that South Norfolk CCG tends to have a lower average weekly cost of continuing healthcare packages for people with a learning disability, compared to their peer CCGs. The information in Figure 4 and Figure 5 shows that residential packages of NHS continuing healthcare for people with a mental health need and/or a physical disability tend to cost less than domiciliary packages of care.

⁴ The figure of £49,000,000 full year spend is an estimate based on figures supplied to Healthwatch Norfolk by the NEL CSU for Week 24 of the financial year 2016-2017. The four CCGs report spending approximately £60,000,000 per year on NHS continuing healthcare (personal communication with Rachael Peacock of Norwich CCG, 13th January 2017).

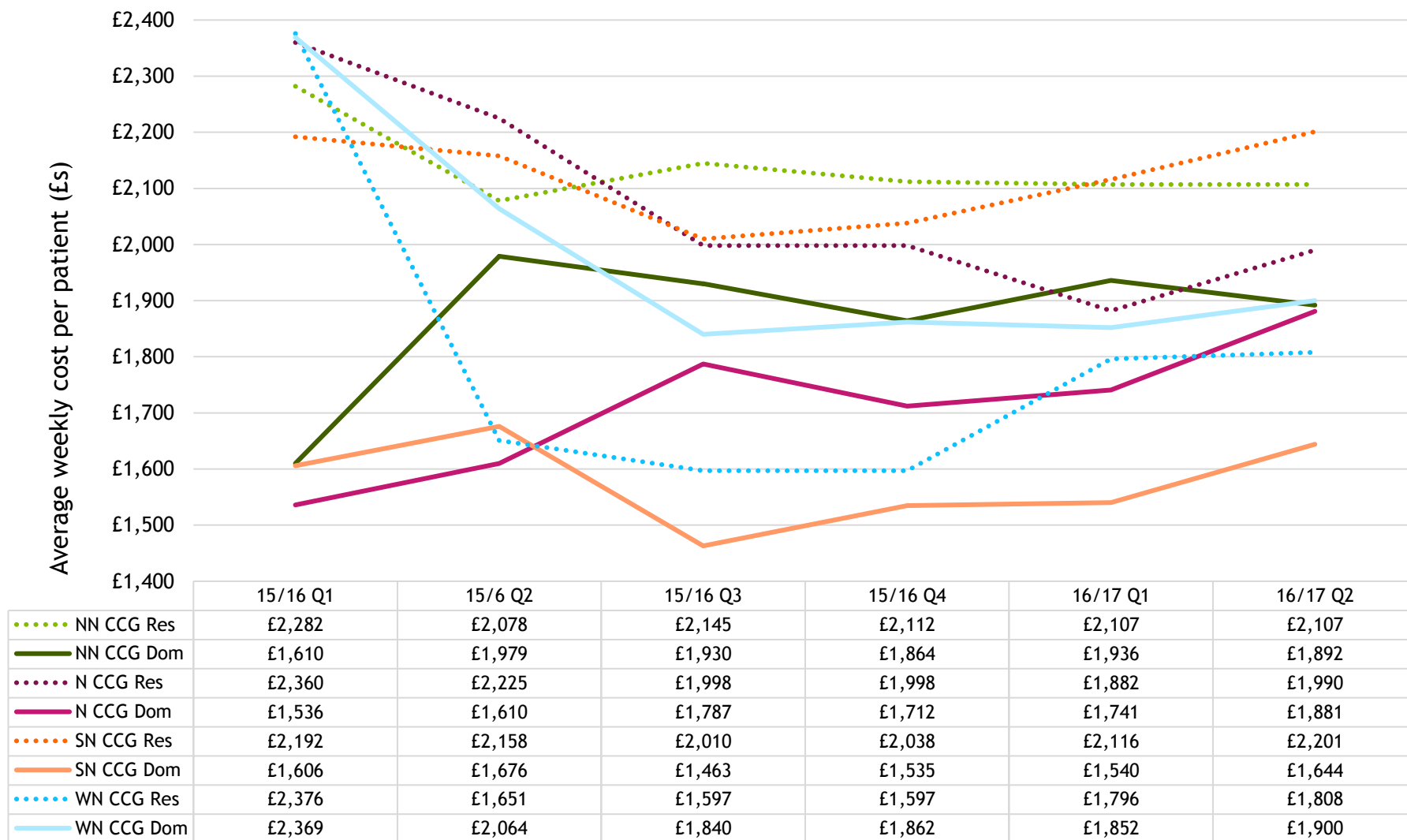


Figure 3. Cost of residential and domiciliary packages of continuing healthcare for people with a learning disability [Q1 2015/16 to Q2 2016/17] funded by North, South, Norwich and West Norfolk CCGs

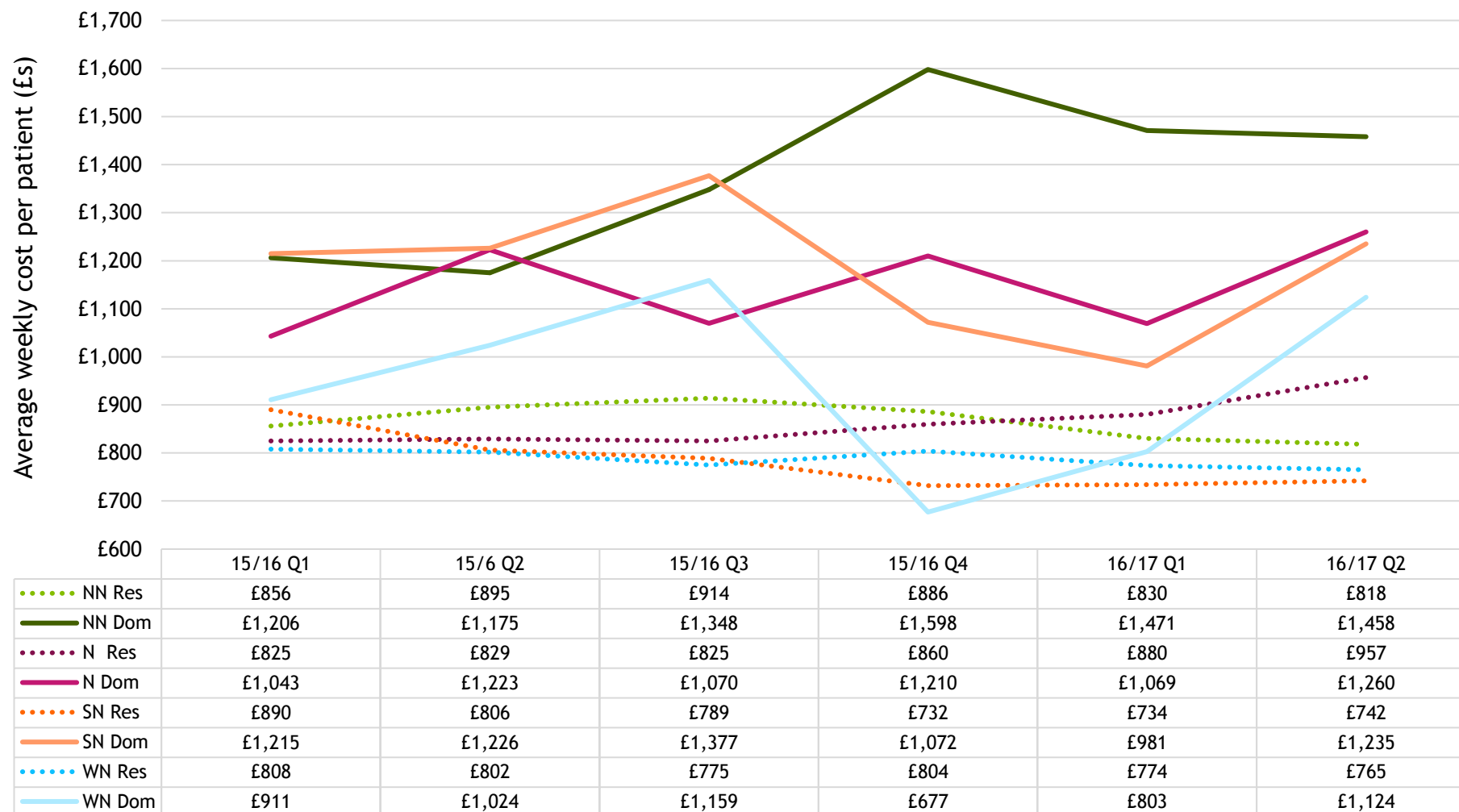


Figure 4. Cost of residential and domiciliary packages of continuing healthcare for people with a mental health need [Q1 2015/16 to Q2 2016/17] funded by North, South, Norwich and West Norfolk CCGs

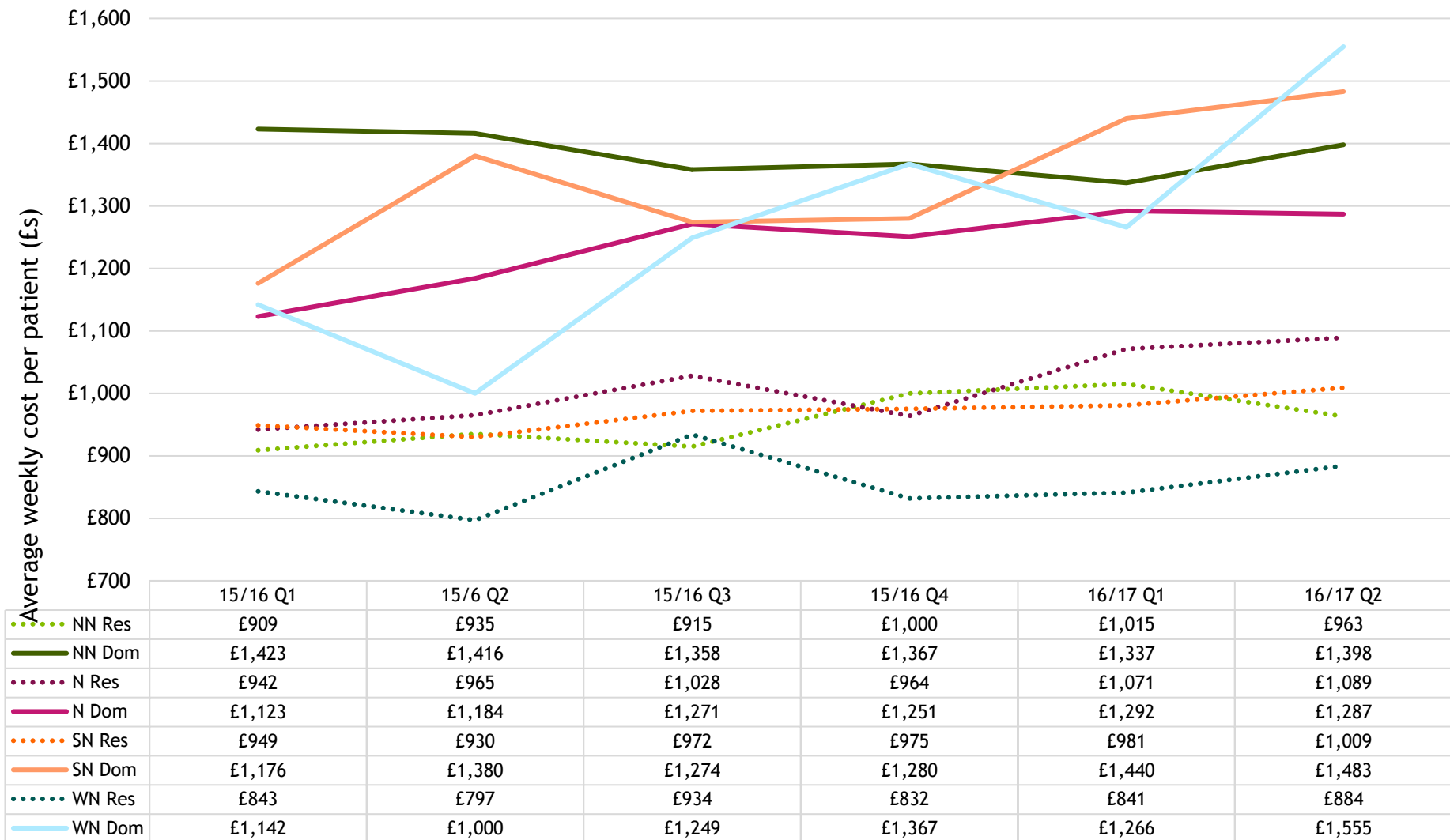


Figure 5. Cost of residential and domiciliary packages of continuing healthcare for people with a physical disability [Q1 2015/16 to Q2 2016/17] funded by North, South, Norwich and West Norfolk CCG

3.2 Complaints and outcomes

The overall number of complaints about NHS continuing healthcare between March 2015 and February 2016 and between March 2016 and August 2016 for patients of the four CCGs are shown in Table 8 and the outcome of these complaints can be found in Tables 9 and 10. Types of complaints made are shown in Figure 6 overleaf.

Table 8

Total number of complaints about NHS continuing healthcare between March 2015 and August 2016 for Norwich, North, South and West Norfolk CCGs

CCG	March 2015 - February 2016	March - August 2016
North Norfolk CCG	22	3
Norwich CCG	8	2
South Norfolk CCG	11	5
West Norfolk CCG	4	3
Total	45	13

Table 9

Outcome of NHS continuing healthcare complaints made between March 2015 and February 2016

March 2015 to February 2016							
CCG	Total number	Outcome					
		Not upheld	Partially upheld	Upheld	Open	N/A	Withdrawn
North Norfolk CCG	22	6	8	6	0	2	0
Norwich CCG	8	3	2	2	0	1	0
South Norfolk CCG	11	1	4	3	0	1	0
West Norfolk CCG	4	1	1	1	0	1	0
Total	45	11	15	14	0	5	5

Table 10

Outcome of NHS continuing healthcare complaints made between March-August 2016

March 2016 to August 2016							
CCG	Total number	Outcome					
		Not upheld	Partially upheld	Upheld	Open	N/A	Withdrawn
North Norfolk CCG	3	0	0	1	1	1	0
Norwich CCG	2	0	0	2	0	0	0
South Norfolk CCG	5	0	0	3	0	1	1
West Norfolk CCG	3	0	0	3	0	0	0
Total	13	0	0	9	1	2	1

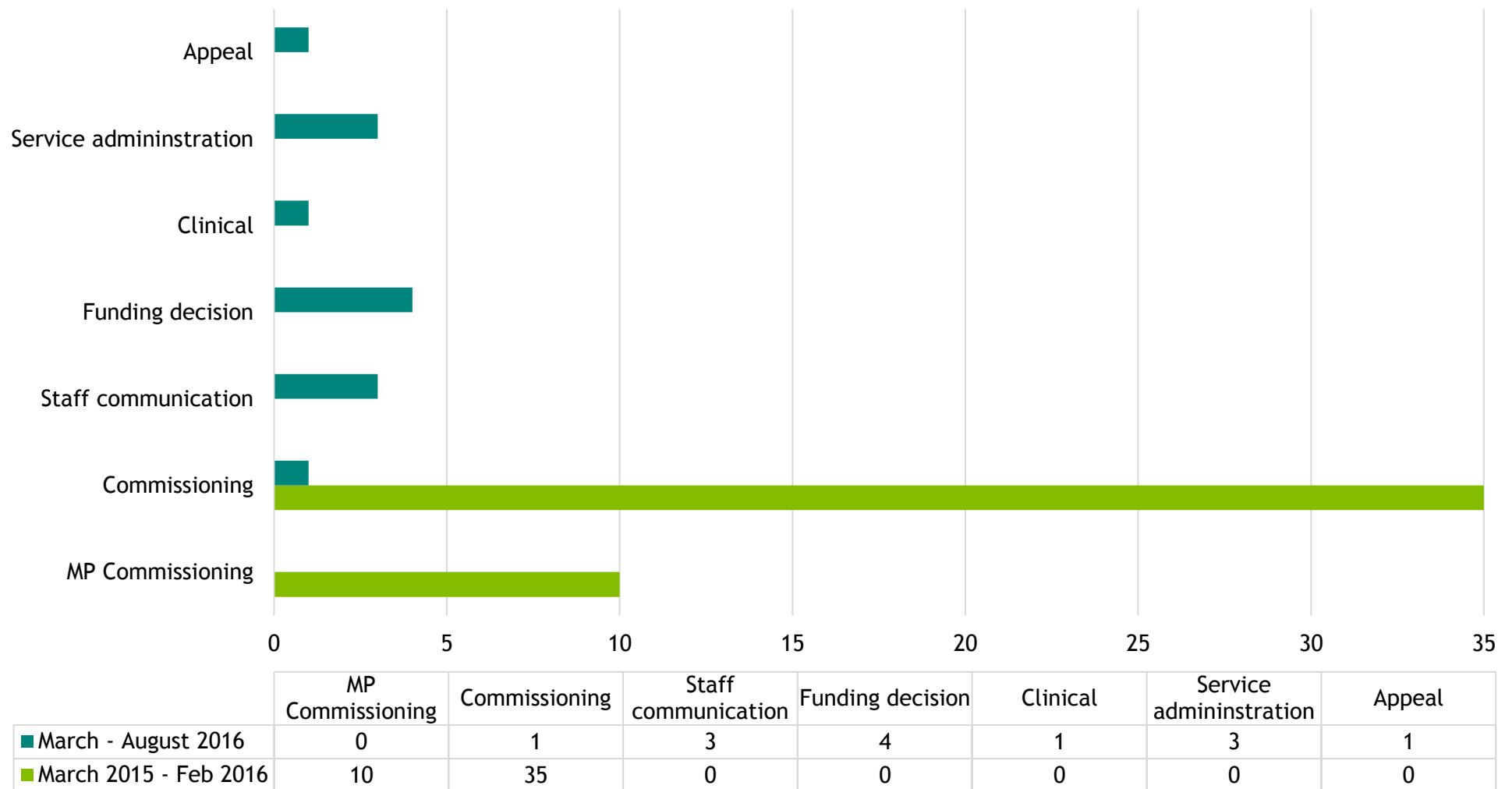


Figure 6 The type [and number] of complaints made about NHS continuing healthcare in March 2015 to February 2016 and March 2015 to February 2016 for patients of Norwich, North, South and West Norfolk CCGs

In the twelve month period March 2015 to February 2016 there were 45 complaints in total and in the six month period March - August 2016 there were 13. The information displayed in Figure 6 shows that commissioning complaints were the most dominant type of complaint in the period March 2015 to February 2016 but there was only one commissioning complaint in the six month period March - August 2016. In the more recent period, the figures suggest a decrease in the overall number of complaints and a shift towards a different type of complaint. For example, in the earlier period (prior to the adoption of a standard protocol for NHS continuing healthcare for all CCGs) there are no complaints about funding but four funding complaints can be observed in the period following implementation. In the latter period there are complaints about staff communication (3) and administration of the service (3) whereas these are not reported in the earlier period. For the respective CCGs, a summary of the changes in the figures is shown below in Table 11 and an overview of all changes is shown in Figure 7.

Table 11

Difference [decrease / increase] in the number of complaint types between March 2015-February 2016 and March-August 2016 for patients of Norwich, North, South and West Norfolk CCGs

Complaint types & outcomes	North Norfolk CCG	Norwich CCG	South Norfolk CCG	West Norfolk CCG	Difference (number)
Total	19	6	6	1	32
MP Commissioning	7	1	1	1	10
Commissioning	15	7	10	2	34
Staff communication	0	0	0	3	3
Funding decision	2	1	1	0	4
Clinical	0	1	0	0	1
Service administration	0	0	1	2	3
Appeal	1	0	0	0	1
Not upheld	6	3	1	1	11
Partially upheld	8	2	4	1	15
Upheld	5	0	0	2	5
Open	1	0	0	0	1
N/A	1	1	0	1	3
Withdrawn	0	0	1	0	4

Key

decrease

increase

no change

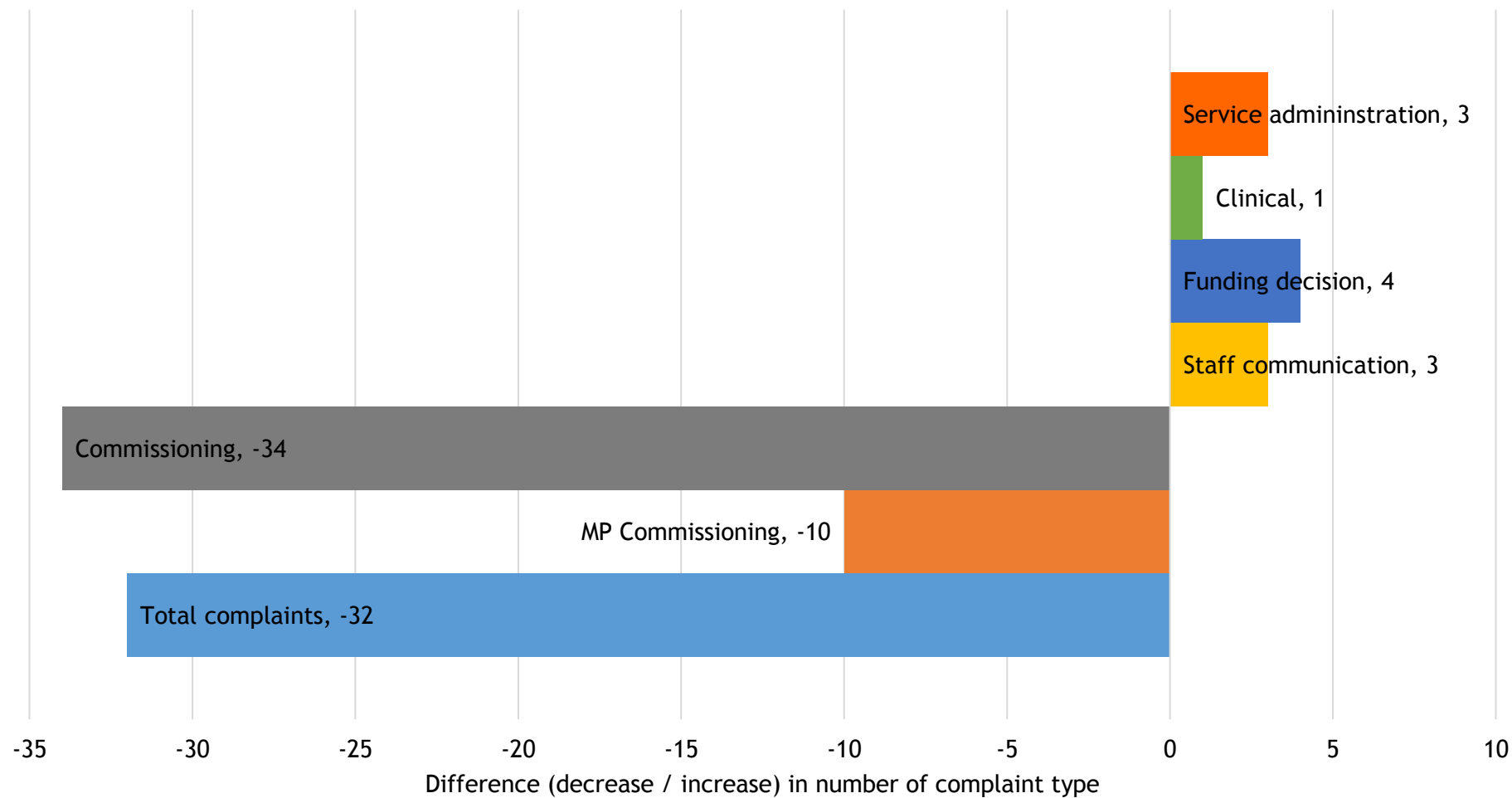


Figure 7. Changes in the number of NHS continuing healthcare complaint types before and after adoption of new arrangements for decision making [difference between March 2015- February 2016 and March-August 2016 for patients of Norwich, North, South and West Norfolk CCGs]

3.3 Appeals

The number, type and outcomes of appeals in respect of NHS continuing healthcare decisions are shown overleaf in Table 12. As observed with complaints about NHS continuing healthcare, the number and type of appeals in the (six month) period March - August 2016 is lower than the (12 month) period March 2015 - February 2016.

North Norfolk CCG appear to have a similar number of appeals between the two time periods. Norwich CCG experienced a drop in number of appeals from 9 in the period March 2015-February 2016 to 1 in the period March-August 2016 which is far fewer than might be expected. Similarly, West Norfolk CCG experienced a drop in the number of appeals from 11 in the period March 2015-February 2016 to 1 in the period March-August 2016, which is far fewer than might be expected using the previous year as a baseline. South Norfolk CCG figures - 6 as compared with 11 - are in line with that which might be expected (based on six months of a twelve month period).

The appeals figures would suggest that the overall number of appeals at the 6-month point for 2016 data are less than what would be expected (based on figures for the previous 12-month period). Reflecting upon the complaints figures for the two periods of time, it could be reasonably construed that a smaller number of complaints leads to a smaller number of appeals.

This is reflected in the outcomes of appeals also. Changes in the number of NHS continuing healthcare decision appeals before and after adoption of new arrangements for decision making (difference between March 2015- February 2016 and March-August 2016) are shown in Figure 7.

Table 12

Number, type and outcome of appeals about NHS continuing healthcare decisions [March 2015- February 2016 and March-August 2016 for patients of Norwich, North, South and West Norfolk CCGs]

CCG	Number of appeals	Type of appeal		Outcome					
		Current	Case still open	Closed: Decision upheld locally	Closed: No rationale received	Closed: Decision overturned locally	Open: As a retrospective assessment	Closed: Passed back to current team	Closed: No response
March 2015 to February 2016									
North Norfolk CCG	6	6	2	3	0	0	0	1	0
Norwich CCG	9	9	2	5	1	1	0	0	0
South Norfolk CCG	14	14	2	6	2	3	0	0	1
West Norfolk CCG	11	11	0	2	3	4	2	0	0
Total	40	40	6	16	6	8	2	1	1
March 2016 to August 2016									
North Norfolk CCG	7	7	6	1	0	0	0	0	0
Norwich CCG	1	1	1	0	0	0	0	0	0
South Norfolk CCG	6	6	3	1	2	0	0	0	0
West Norfolk CCG	1	1	1	0	0	0	0	0	0
Total	15	15	11	2	2	0	0	0	0

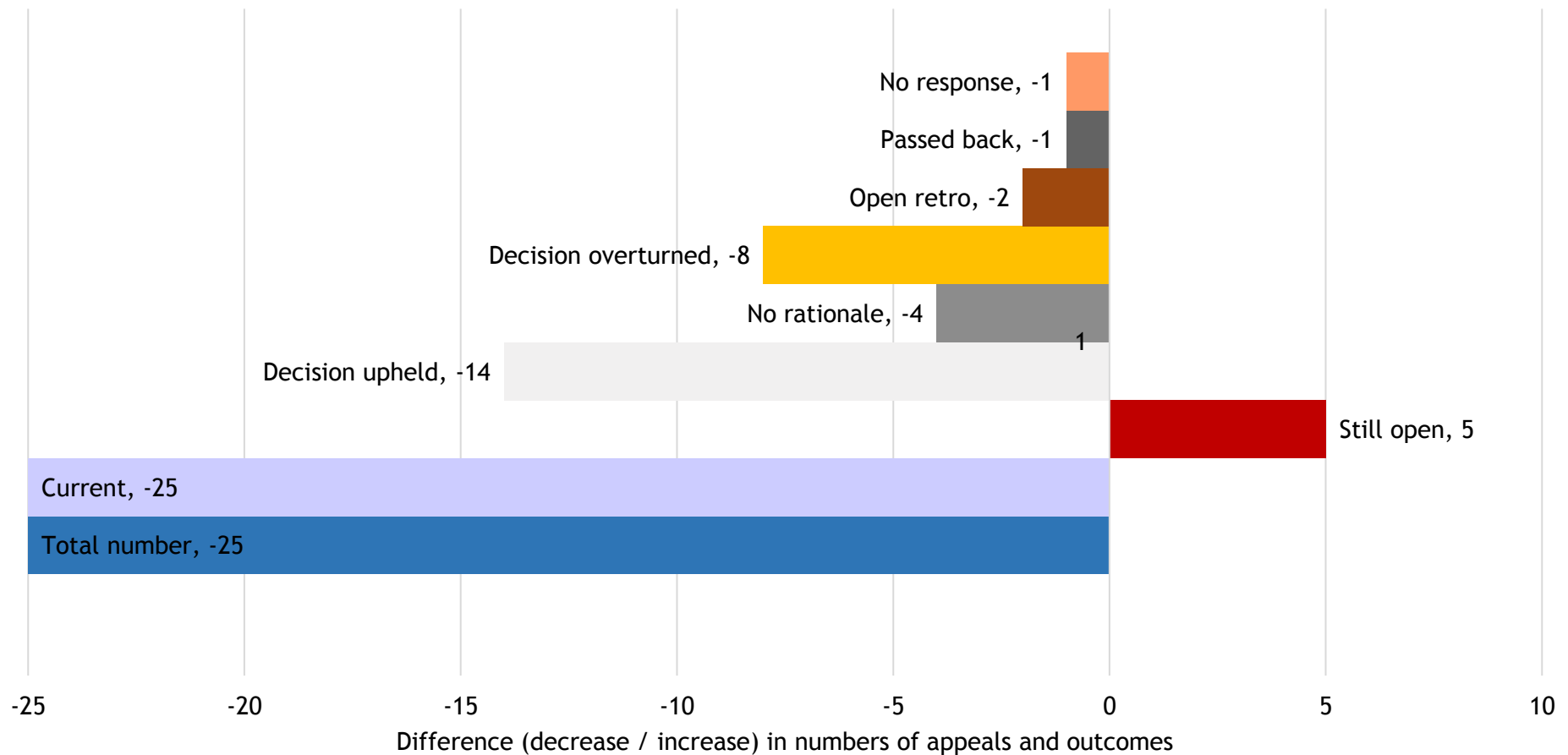


Figure 7. Changes in the number of NHS continuing healthcare decision appeals before and after adoption of new arrangements for decision making [difference between March 2015- February 2016 and March-August 2016 for patients of Norwich, North, South and West Norfolk CCGs]

3.4 Comparison of complaints before and after adoption of new arrangements for NHS continuing healthcare decisions

To get a more accurate understanding of any changes in the number and type of complaints as a result of the new arrangements for decision making put in place by the four CCGs, it is necessary to compare two similar time periods. For this purpose of this exercise, a comparison of the number and type of complaints made between Quarter 1 April - June 2015 compared with those made between Quarter 1 April - June 2016 was carried out. Table 13 shows the number of complaints for each quarter and the outcome. Figure 8 overleaf displays the categories of complaints handled during this period of time.

Table 13

Number of complaint and type of outcome [Quarter 1 2015-2016 & Quarter 1 2016-2017]

Number of complaints		
	Quarter 1 2015-2016	Quarter 1 2016-2017
April	1	4
May	2	3
June	6	0
Total	9	7
Outcome of complaints		
Upheld	1	6
Partially upheld	4	0
Not upheld	4	0
Ongoing	0	1

The number of complaints about NHS continuing healthcare do not greatly differ between Quarter 1 2015-2016 and Quarter 1 2016-2017 i.e. there was no increase in the number of complaints regarding NHS continuing healthcare following the adoption of the new protocol to standardize the decision-making process between the four CCGs - there were 2 less. More complaints were upheld in Quarter 1 2016-2017 compared with Quarter 1 2015-2016.

What is noticeable, is the difference in the type of complaint that is being processed. In Quarter 1 2016-2017 there were no complaints regarding the quality of service or care received or about policy or contract issues as compared with Quarter 1 2015-2016. There is however, a slight shift towards categories of complaints about staff communication and funding decisions in the three month period of Quarter 1 2016-2017 following the adoption of the new protocol.

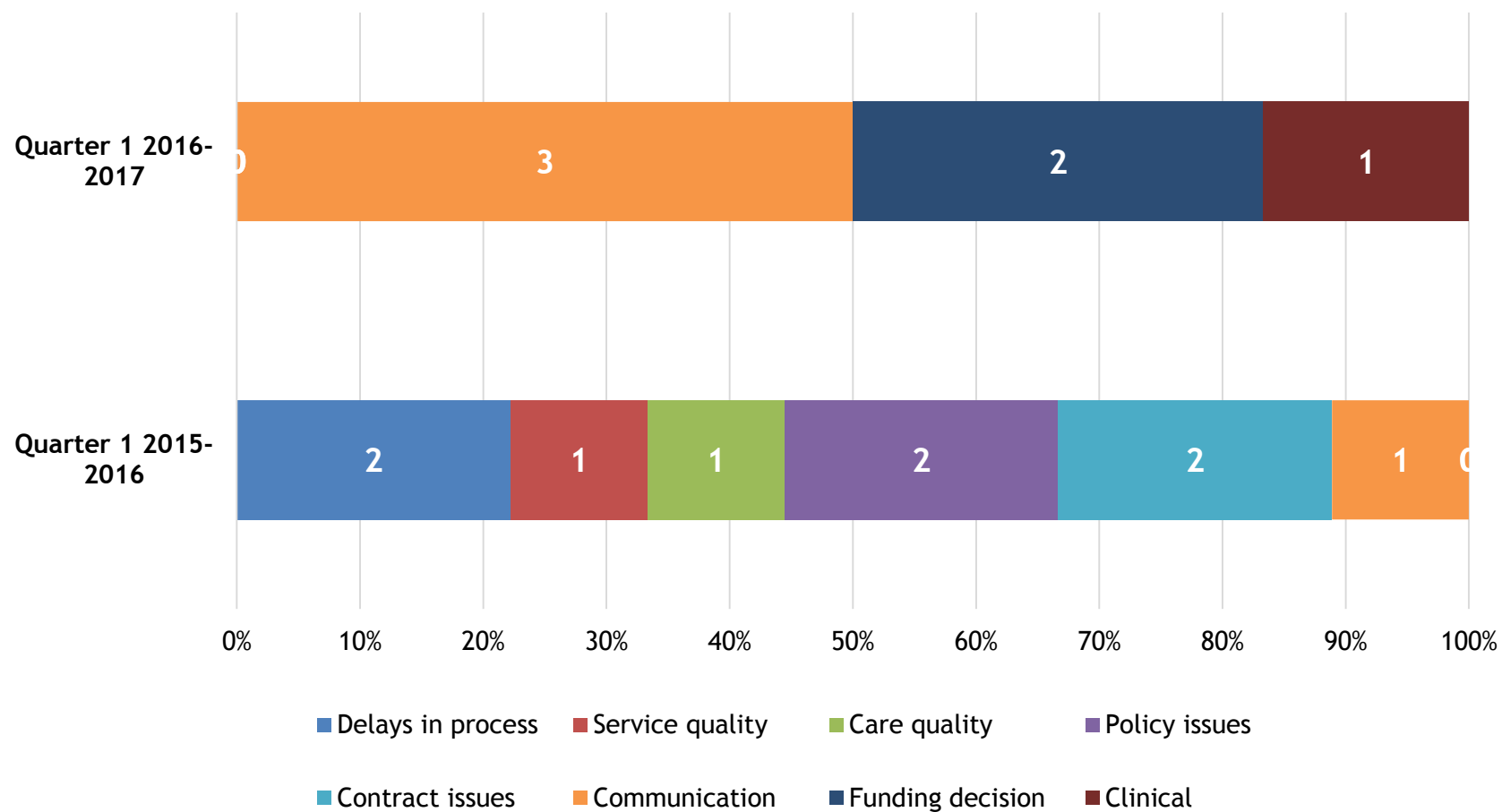


Figure 8. Categories of complaints about NHS continuing healthcare - comparison of Quarter 1 [financial years 2015/16 and 2016/17]

3.5 Feedback from patients, families and advocates

3.5.1 Respondents

In this section, feedback from 53 individuals will be shared. Between November 2016 and January 2017, 49 people responded to the Healthwatch Norfolk survey asking for feedback on NHS continuing healthcare in the last two years (2015 and 2016) - see Table 14 below. In addition, a further four individuals responded to our call for comments through the Healthwatch Norfolk newsletter resulting in one face to face conversation and three telephone conversations. The majority of respondents to our call for feedback were friends or relatives (49%) or a carer (43%) of the person receiving continuing healthcare. This means that the feedback reflects the views and experiences of family members, carers and friends but this is not unexpected given that many recipients of NHS continuing healthcare are very unwell and/or have a family member, friend, carer or advocate.

Table 14

Status of 53 respondents

Respondents	Number
The person receiving continuing healthcare	4
A friend or relative of the person receiving continuing healthcare	26
A carer of the person receiving continuing healthcare	23
Other	0
Total	53

With respect to assessment for NHS continuing healthcare, the majority of those giving feedback said that their family member/the person they cared for had either been assessed or were waiting to be assessed (see Figure 9).

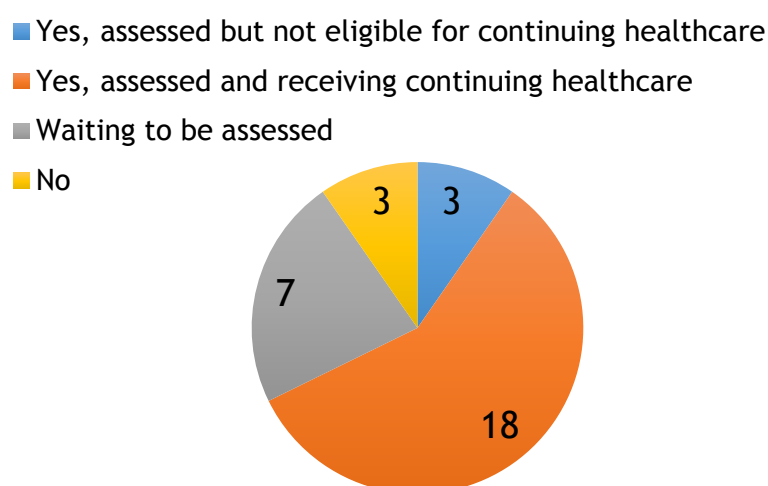


Figure 9. Responses to the question "Has your cared for/friend/relative been assessed or started receiving continuing healthcare in 2015 or 2016?" [32 out of 49 respondents]

3.5.2 Response to “I” statements

The responses of 24 family members, friends and carers of people receiving NHS continuing healthcare are shown below in Table 15. The total number of people giving responses to the “I” statements is quite small and caution is advised in drawing any meaningful conclusion from a small sample.

Table 15

Response to “I” statements by family members, friends and carers of people receiving NHS continuing healthcare

“I” statement	Response Number (%) of respondents					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
“I believe they receive care and support that helps them live the best life they can and promotes their independence”	5 (22%)	3 (13%)	4 (17%)	7 (30%)	4 (17%)	23
“I believe the care and support they receive is designed around their needs”	5 (22%)	5 (22%)	4 (17%)	6 (26%)	3 (13%)	23
“I believe they were given choice where possible about their care arrangements	5 (23%)	4 (18%)	3 (14%)	8 (36%)	2 (9%)	22
“I am happy that they have been able to shape their care and support plan to meet their needs and to help them to live as they wish”	7 (32%)	6 (27%)	2 (9%)	4 (18%)	3 (14%)	22
“I believe that their rights as an individual have been respected”	2 (9%)	5 (23%)	6 (27%)	5 (23%)	4 (18%)	22
“I believe those delivering their care provide a high quality service for them”	2 (9%)	4 (18%)	9 (41%)	4 (18%)	3 (14%)	22
“I believe the money spent on their care is used effectively and efficiently”	4 (18%)	2 (9%)	10 (45%)	4 (18%)	2 (9%)	22
“I was given information about personal health budgets and it was explained to me in a way I understood”	4 (17%)	6 (25%)	6 (25%)	6 (25%)	2 (8%)	24
“I was made aware of how to complain or raise any concerns I may have”	5 (20%)	7 (29%)	8 (33%)	4 (17%)	0	24

Responses to the “I” statements were varied and spread fairly evenly across the categories of agreement and disagreement. More people disagreed than agreed

(59% vs 32%) that individuals receiving NHS continuing healthcare are able to shape their care and support plan and few agreed that they were made aware of how to complain or raise any concerns they had (49% vs 17%).

3.5.3 Raising concerns and reporting satisfaction

People were asked if they had needed to raise any concerns about NHS continuing healthcare, or had needed to make a complaint and their responses are shown below in Figure 10.

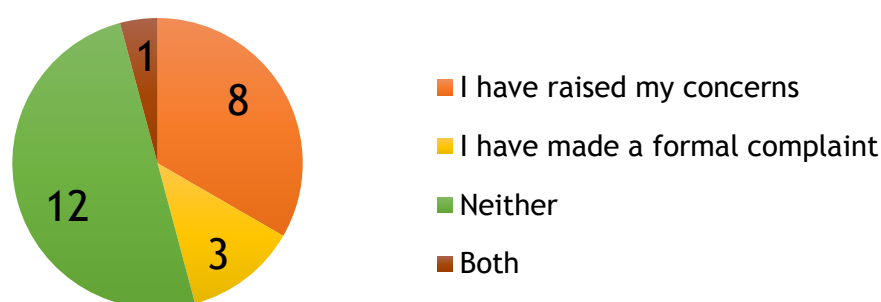


Figure 10. Raising concerns and making complaints [as reported by 24 respondents]

People were asked if they had any dealings with the NEL CSU and if so, how they would rate their satisfaction with them. There were 8 responses to this question with one person indicating they were very dissatisfied, 2 were dissatisfied and 5 were neither satisfied nor dissatisfied (none were satisfied).

3.5.4. Feedback on experiences

A total of 53 people gave feedback on their experiences of NHS continuing healthcare and it should be born in mind that these findings cannot be taken as representative of all recipients of NHS continuing healthcare or their family members/carers.

Amongst the feedback on experiences of NHS continuing healthcare that we received, the major themes were:

- Most people giving feedback on current NHS continuing care packages were **satisfied with the quality of the care** being provided
- The decision that a person is not eligible for funded NHS continuing healthcare often comes as a **unwelcome surprise**; people say they don't understand the reasons they were given or the way in which in the decision/outcome was explained to them
- People find their journey through the NHS continuing healthcare process to be **complex and stressful**; a lot of energy is required to make it through to the end of the process

- People feel entitled: **an expectation of receiving some level of funded, medium to long term NHS care is the norm** - all NHS care is free so why isn't continuing healthcare?
- Family members are often unprepared for the situation they find themselves in when a loved-one has ongoing and possibly long term care needs; **financial planning for care needs** are not routinely considered or discussed
- The format and tone of written communication i.e. **letters to next-of-kin, family members and carers are widely considered to be unnecessarily harsh, disrespectful and at times, threatening**, especially those written communications about the cost of care or request for payment. Requests for payments for care are often interpreted as demands for payment and at times, for unexpectedly large sums of money (one person quoted a sum of £17,000) within a very short deadline

The most pertinent messages to be taken from the feedback are:

1. **Expectations of NHS continuing healthcare funding do not match reality.** Entitlement to an NHS continuing healthcare referral is frequently conflated with eligibility for funded NHS continuing healthcare; more could be done to improve the accuracy of information about NHS continuing healthcare and what to expect during the referral and assessment process.
2. Family members, friends and carers can find the process complex and overwhelming; **the support, advice and advocacy provided by some organisations to those going through the process is highly valued** and such support services could help improve communication, minimize misunderstandings and potentially reduce the number of complaints received about the NHS continuing healthcare referral, assessment and decision-making process.

"I'm not actually sure what a funded package of continuing care actually is"

"they keep stringing me along with every so often putting forward various home care packages for the 'panel' to consider, who always turn them down & I'm never given considered reasons why that is."

"mum didn't have any problem being given CHC funding"

"Got there in the end but it took determination and was frustrating at times. Now that we have it I feel very grateful but I know that most people will not qualify"

"By no means am I complaining about the quality of care she gets because the carers themselves are excellent"

"Sad to say, I have no time at all for CHC and don't trust them"

"the patient was assessed last year and deemed not to be eligible, despite deterioration needing carers and night care"

"applied and rejected but not really told why...everything is money based with no interest in welfare"

"we are waiting for my father to be assessed but it does take a long time for the appointments"

"I have to deal with the TOTAL lack of understanding and support..."

4. Summary of findings

A comparison of figures from the first two quarters of the financial year 2015-2016 with those of the first two quarters for 2016-2017 suggest little or no change in the number of open packages of NHS continuing healthcare for people with a learning disability. The number of open packages of NHS continuing healthcare for people with a mental health need have decreased slightly in the first half of this financial year whilst open packages for people with a physical disability have risen.

For Norwich, North and South Norfolk CCGs it is possible to see a slight upward trend from Q1 2015/16 to Q2 2016/17 in the number of domiciliary NHS continuing healthcare packages. The information on average costs per patient per package show that domiciliary care packages cost more than residential packages.

Figures on waiting times between a referral being made and an assessment taking place show that patients of the West Norfolk CCG spend the longest time waiting - an average of 105 days - whilst patients of South Norfolk CCG are assessed on average 30 days after referral.

At week 24 (of 52) in the financial year, there were 102 patients with a Personal Health Budget for NHS continuing healthcare; 10 personal health budgets had ended during that time whilst 13 had started. Healthwatch Norfolk estimated that collectively, the four CCGs are spending at least £49,000,000 per year on NHS continuing healthcare for 800 patients and through personal communication with the CCGs we were informed the figure is closer to £60,000,000. We have found little evidence to suggest that the four CCGs have altered their spending behaviours between 2015-2016 and 2016-2017.

The information on complains about NHS continuing healthcare show that 45 complaints were handled in the 12-month period March 2015-February 2016 compared to 13 complaints handled in the 6-month period March - August 2016. Complaints about commissioning issues were much more dominant in the year before the adoption by the CCGs of the new protocol for decision-making (figures for 2015-2016) and. In this financial year, fewer complaints have been made but of them are being upheld than in the previous year. There may be a number of reasons for this which might include:

- The adoption of the new protocol for NHS continuing healthcare has led to an improvement in the overall process, leading to a reduction in cause for complaints
- The new protocol has led to improvements in some aspects of the NHS continuing healthcare process (i.e. commissioning) but not in others (i.e. communication and funding)
- The NEL CSU has changed the way in which it logs, processes or categories complaints between the two financial years or the complaints process has changed

- Patients, family members and carers are becoming less aware on how to go about making a complaint

Whilst caution is required in attaching significance to the responses of a small number of people (24), slightly more people disagreed (59% vs 32%) than agreed that individuals receiving NHS continuing healthcare are able to shape their care and support plan and that they were made aware of how to complain or raise any concerns they had (49% vs 17%). Three of the 24 respondents had made a formal complaints and 8 had raised concerns. The very small number of respondents (8) who had had dealings with NEL CSU tended to be dissatisfied or unsure about their level of satisfaction with them.

When comparing complaints recorded for Quarter 1 of 2015-2016 and Quarter 1 of 2016-2017 i.e. a similar time period, a small difference in the number of complaints can be observed. In Quarter 1 2015-2016 there were 9 complaints and in Quarter 1 2016-2017 there were 7. The type (category) of complaint is seen to shift from complaints of a commissioning nature towards complaints about communication and funding decisions. Between the two periods it was also possible to observe a smaller number of appeals (probably as a result of fewer complaints).

A total of 53 people responded to the call for feedback on NHS continuing healthcare experiences in the last two years. Forty-nine individuals completed an online survey and four contacted Healthwatch Norfolk in person to give their views. Most survey respondents were carers of people who had been assessed and were receiving care and a smaller proportion were carers of people still waiting.

The numbers of respondents are fairly small therefore caution is required however, the recurring, take-home messages are that:

- There is a need for clear and accurate information about the NHS continuing healthcare referral and assessment process i.e. what to expect, eligibility and what each decision means.
- Improvement is needed in both verbal and written communication of the different stages the process, the outcome of each stage- and ***particularly for the notification of decisions including funding decisions with reasons why*** and in ***written requests for payment for NHS continuing healthcare.***

4.1 Concluding statement

NHS continuing healthcare is a complex topic. In summary, in the context of the information with which we were supplied by the NEL CSU for the period of time under scrutiny; we could not find any specific evidence that suggests the adoption of a standardised protocol for decision-making about NHS continuing healthcare by four of Norfolk's CCGs has led to an increase in complaints and appeals or to a reduction in spending. Fewer complaints about NHS continuing healthcare have

been made in the current financial year (2016-2017) leading to fewer appeals however the way in which complaints are categorised by the NEL CSU may have contributed in some part to the differences observed.

For Norwich, North and South Norfolk CCGs it is possible to see a slight upward trend from Q1 2015/16 to Q2 2016/17 in the number of domiciliary NHS continuing healthcare packages which tend to have a higher average weekly cost compared with residential packages. The nature of complaints has shifted slightly towards communication and funding issues. Family members, carers and patients appear to conflate entitlement to referral with eligibility for funded NHS continuing healthcare. Communication with patients, family members and carers on all aspects of NHS continuing healthcare could be greatly improved.

Appendix 1. Information about NHS Continuing Healthcare requested from the North East London Commissioning Support Unit

Provision of April 2015 to September 2016 data

Data Schema - formal complaints, appeals, retrospective and Previously Unassessed Periods of Care (PUPOC) data

Field	Format
Complaint Reference	Unique reference number
Date Received	dd/mm/yyyy
Issue / Concern	[Free text description]
Complaint Category	<ul style="list-style-type: none"> • Delays in process • Service Quality • Care Quality • Policy • Contract issues • Clinical Decision • Communication • Funding
Service Provider	<ul style="list-style-type: none"> • NHS CONTINUING HEALTHCARE Retrospective • NHS CONTINUING HEALTHCARE Clinical • NHS CONTINUING HEALTHCARE Finance • NHS CONTINUING HEALTHCARE Appeals • NHS CONTINUING HEALTHCARE PHB
CCG Area	<ul style="list-style-type: none"> • North Norfolk CCG • West Norfolk CCG • South Norfolk CCG • Norwich CCG

Data Schema - NHS CONTINUING HEALTHCARE provision

Field	Format
ID	Unique reference number
Setting	<ul style="list-style-type: none"> • Care home • Own home • Other
Cost	GBP per week
Personal Health Budget	<ul style="list-style-type: none"> • Yes • No
CCG Area	<ul style="list-style-type: none"> • North Norfolk CCG • West Norfolk CCG • South Norfolk CCG • Norwich CCG

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Norfolk Health Overview and Scrutiny Committee appointments

Report by Maureen Orr, Democratic Support and Scrutiny Team Manager

The Committee is asked to appoint a member to Great Yarmouth and Waveney Joint Health Scrutiny Committee and a member to act as link with the James Paget University Hospital NHS Foundation Trust.

1. Great Yarmouth and Waveney Joint Health Scrutiny Committee

- 1.1 Great Yarmouth and Waveney Joint Health Scrutiny Committee consists of three members appointed by Norfolk Health Overview and Scrutiny Committee (NHOSC) and three members appointed by Suffolk Health Scrutiny Committee. The joint committee meets quarterly, with the next meeting scheduled for 4 April 2017.
- 1.2 There is one vacancy for an NHOSC member on the joint committee. Nominations are not required to be in line with the political balance of Norfolk County Council. Other members of NHOSC can substitute for the joint committee members as and when required.
- 1.3 The terms of reference for the joint committee require NHOSC to appoint three members. One must be the Great Yarmouth and Waveney Borough Council member on NHOSC and the other two may be appointed from members representing residents in the Great Yarmouth area or adjoining districts to Great Yarmouth and Waveney where a proportion of their residents look in the first instance to the James Paget University Hospital NHS Foundation Trust for acute services.
- 1.4 The current NHOSC appointees to the joint committee are:-

Mr M Carttiss
Mrs S Weymouth (the Great Yarmouth Borough Council appointee to NHOSC)
Vacancy

2. NHOSC link appointments

- 2.1 NHOSC appoints members to act as link members with local NHS Trusts and Clinical Commissioning Groups (CCGs). The role is to attend the Trust Board / Council of Governors or CCG Governing Body meetings held in public to keep abreast of developments and to raise with NHOSC any matters which may warrant the committee's attention. NHOSC also appoints substitutes to act in these roles.

- 2.2 There is one **vacancy** for a link member for the James Paget University Hospitals NHS Foundation Trust (JPUH NHS FT). Mrs M Stone currently serves as the substitute link member for this trust.

The forthcoming meetings of JPUH NHS FT are as follows:-

Board of Directors, 9.30am start:-

24 February 2017

31 March 2017

28 April 2017

Council of Governors, 12.30pm start:-

10 March 2017

3. Action

- 3.1 The Committee is asked to:-

- (a) Appoint a member to Great Yarmouth and Waveney Joint Health Scrutiny Committee in line with its terms of reference (see paragraph 1.3 above).
- (b) Appoint a link member for the James Paget University Hospitals NHS Foundation Trust.



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Norfolk Health Overview and Scrutiny Committee

ACTION REQUIRED

Members are asked to suggest issues for the forward work programme that they would like to bring to the committee's attention. Members are also asked to consider the current forward work programme:-

- whether there are topics to be added or deleted, postponed or brought forward;
- to agree the briefings, scrutiny topics and dates below.

Proposed Forward Work Programme 2017

<i>Meeting dates</i>	<i>Briefings/Main scrutiny topic/initial review of topics/follow-ups</i>	<i>Administrative business</i>
6 Apr 2017	<p><u>Children's mental health services in Norfolk</u> – scrutiny of the service after a full year of operation following the Local Transformation Plan changes</p> <p><u>IC24's NHS 111 and GP out of Hours Service in central and west Norfolk</u> – an update from IC24 and Norwich CCG, further to the NHOSC meeting on 14 April 2016.</p>	
25 May 2017		
20 July 2017		

NOTE: These items are provisional only. The OSC reserves the right to reschedule this draft timetable.

Provisional dates for report to the Committee / items in the Briefing in 2017

Provisional – 26 Oct 2017 – Ambulance Response and Turnaround Times in Norfolk - on 13 Oct 2016 NHOSC received a report from the East of England Ambulance Service NHS Trust and the Norfolk & Norwich University Hospitals NHS Trust. Agreed that it *may* wish to look at the subject again in a year's time.

26 Oct 2017 – *In the NHOSC Briefing* – Introduction of the Primary Care Education and Training Tariff – update from Mr I Newton, Department of Health (follow up to Members' informal meeting with Mr Newton on 29 Sept 2016).

Members serving on Task & Finish Groups

Task & finish group	Membership	Progress
Children's Services Committee Task & Finish Group Review Review of access to support and interventions for children's emotional wellbeing and mental health	From NHOSC Mrs M Stone (appointed 14 April 2016) Ms E Corlett (Chairs the T&F Group and joined NHOSC subsequent to its establishment)	The group reported to CS committee on 24 January 2017. A copy of the T&F Group report will be included in NHOSC agenda papers for 6 April 2017.

Main Committee Members have a formal link with the following local healthcare commissioners and providers:-

Clinical Commissioning Groups

North Norfolk	-	M Chenery of Horsbrugh (substitute Mr David Harrison)
South Norfolk	-	Dr N Legg (substitute Mrs M Stone)
Gt Yarmouth and Waveney	-	Mrs M Stone (substitute Mrs M Fairhead)
West Norfolk	-	M Chenery of Horsbrugh (substitute Mrs S Young)
Norwich	-	Mrs M Stone (substitute Ms E Corlett)

NHS Provider Trusts

Queen Elizabeth Hospital, King's Lynn NHS Foundation Trust	-	M Chenery of Horsbrugh (substitute Mrs S Young)
Norfolk and Suffolk NHS Foundation Trust (mental health trust)	-	M Chenery of Horsbrugh (substitute Mrs M Stone)
Norfolk and Norwich University Hospitals NHS Foundation Trust	-	Dr N Legg (substitute Mrs M Stone)
James Paget University Hospitals NHS Foundation Trust	-	Vacancy (substitute Mrs M Stone)

Norfolk Community Health and Care NHS
Trust

- Mrs J Chamberlin
(substitute Mrs M Stone)

Norfolk Health Overview and Scrutiny Committee 23 February 2017

Glossary of Terms and Abbreviations

ADASS	Association of Directors of Adult Social Services
CCG	Clinical Commissioning Group
CCRP	Complex Case Review Panel
CHC	Continuing Healthcare
CQC	Care Quality Commission
CSU	Commissioning Support Unit
DoH	Department of Health
DOLS	Deprivation of liberty safeguards
Dom	A domiciliary care setting (i.e. a patient's own home)
DST	Decision Support Team
DWP	Department of Work and Pensions
ECHR	European Court of Human Rights
FREDA principles	Fairness, Respect, Equality, Dignity, Autonomy
GB	Governing body
GP	General Practitioner
HOSC	Health Overview and Scrutiny Committee
HWN	Healthwatch Norfolk
HRA	Human Rights Act
ICA	Individual case arrangement
ICES	Integrated Community Equipment Service
LA	Local Authority
LD	Learning Difficulties / Disability
MCA	Mental Capacity Act 2005
MDT	Multi disciplinary team
MH	Mental Health
MUST	Malnutrition Universal Scoring Tool
NCA	Non-contracted activity
NEL CSU	North East London Commissioning Support Unit
NHOSC	Norfolk Health Overview and Scrutiny Committee
N	Norwich
NN	North Norfolk
OT	Occupational therapy
PALS	Patient Advisory Liaison Service
PD	Physical disability
PHB	Personal Health Budget
PUPOC	Previously unassessed periods of care
Res	A nursing / residential care home setting
SALT	Speech and language therapy
SN	South Norfolk

UN	United Nations
WN	West Norfolk
YTD	Year to date