



Improving NHS Continuing Healthcare Communication

A report by Healthwatch Norfolk to the Health Overview & Scrutiny Committee on activities and progress June - November 2018

1. Background

This report provides the committee with a summary of the outcomes of collaborative work between Healthwatch Norfolk and Norfolk Continuing Care Partnership (NCCP) to improve NHS continuing healthcare (NHS CHC) communication with patients and families (next-of-kin). The work focused upon:

- Improving verbal and written communication in the suite of existing (i.e. inherited) template letters including:
 - ⊕ Stages of the process
 - ⊕ Outcome of each stage
 - ⊕ Notification of decisions (including funding decision)
 - ⊕ Appeals
- Improving verbal and written information provided to patients and families such as information leaflets and signposting to further sources
- Ways of capturing real-time feedback from patients and families, on how well they understood the CHC process and how well they were explained to them

2. Activity July to November 2018

2.1 Four half-day workshops were held between July and November 2018, organised by Healthwatch Norfolk. The content of the workshops was designed to cover each of the actions proposed by NCCP to HOSC, allowing time for discussion, feedback and agreeing changes and /or actions. Healthwatch Norfolk asked volunteers and partners from carers support organisations with lived experience of the NHS CHC process and service to help with this work.

2.2 The volunteers who participated each had varied, lived experience as a spouse, family carer or parent of a person who had either; been assessed for NHS CHC and found not eligible, been assessed for NHS CHC, found eligible and receiving continuing healthcare and experience of providing information and advice to others in a similar position.

2.3 NCCP were actively involved in the workshop planning, preparation and follow-up in a variety of ways. The service director attended every workshop alongside a Clinical Lead for each speciality plus staff holding roles involving frequent contact with families and patients. NCCP provided digital and print versions of original template letters and information leaflets and subsequently amended versions.

2.4 The following is a summary of specific feedback, with subsequent action taken by NCCP.

Content / activity	Feedback leading to a change by NCCP:
Workshop 1: Introduction to NHS CHC in Norfolk & Review of Letter Templates	
Reviewing the 10 most frequently used letter templates (out of 40) communicating with patients and families <ul style="list-style-type: none"> • Checklist CHC Not Eligible • Checklist Appeal for Next of Kin • CHC Combined Eligibility and 3 Month Review • Full Process Not Eligible for CHC • Remains Eligible Letter • Funded Nursing Care (FNC) Eligible and For Full Process • FNC Eligible No for Full Process • Not Eligible for FNC or Full Process • Letter for Next of Kin for a person who died whilst on the waiting list • Letter for Next of Kin for a person who died with Assessment Not Completed • Personal Health Budget invitation letter 	<ul style="list-style-type: none"> • Adding extra ‘fields’ to the templates so letters can be better tailored/personalised to the recipients • Several changes the tone of the letters e.g. replacing specific words to improve clarity and understanding and avoid complexity • Removing superfluous information that could lead to confusion or misunderstanding and to keep letters succinct where appropriate • Removal of long hyperlinks in print/paper • Adding organisation names, website addresses and contact telephone numbers • Clear instructions on how to contact NCCP (and who to contact) with any questions • Sending accompanying information leaflet where appropriate
Workshop 2: Care Coordinators, Redrafted Letter Templates, Information leaflets and Real-Time Feedback	
Gathering evidence for the NHS CHC assessment What counts as evidence and what can families and carers do?	<ul style="list-style-type: none"> • During the process of assessment, suggest to families / carers they could record how their loved one is coping day to day, health and support needs, mood and behaviour, taking medication
Review of redrafted letter templates (as detailed above)	<ul style="list-style-type: none"> • All changes proposed had been implemented <p><u>Exception:-</u></p> <ul style="list-style-type: none"> • The entire Decision Support Tool document is sent to a person (and/or next of kin) following an assessment. It is a 52 page document and record of the assessment at a specific point in time. Volunteers suggested providing only a summary of the completed Decision Support Tool for patients /families however <i>this is not possible because the national guidance does not allow it.</i>

Content / activity	Feedback leading to a change by NCCP:
Workshop 2 (cont): Care Coordinators, Redrafted Letter Templates, Information leaflets and Real-Time Feedback	
Information booklet: Central & West Norfolk guide to NHS CHC for patients	<ul style="list-style-type: none"> • This in-house, locally tailored guide to be available on the NCCP website with an option to request a print copy • Addition of the InTran logo & information on accessible formats and language etc.
<p>Capturing real-time feedback</p> <p>Appraisal of existing, in-house patient feedback pro-forma and channels</p> <p>Comparison against examples from elsewhere</p> <ul style="list-style-type: none"> • CHC Patient Satisfaction Survey • Funded Nursing Care (FNC) Patient Satisfaction Survey • Easy Read Patient Satisfaction Survey • Personal Health Budgets (PHB) Customer Satisfaction Survey • Personal Health Budget Quarterly Review Satisfaction Survey • Personal Health Budget Annual Review Satisfaction Survey 	<ul style="list-style-type: none"> • Using size 12 font as a standard • Answer options for patients and/or families • Confine the feedback survey to no more than 2 sides of A4 paper, for speedy completion • Questions to have multiple choice options and tick boxes for ease of use • Include one free text /comment box • Explain there are other ways to give more detailed feedback e.g. via telephone • Include brief description of how feedback is used to improve the service <p>On an ongoing basis:</p> <ul style="list-style-type: none"> • The patient feedback survey will be trialled with 100 people and collated to review themes and trends • There is now a generic email address for giving feedback which is being added to all letters • NCCP already have mechanisms to review complaints and feedback via the Clinical Governance Forum • Healthwatch Norfolk can provide NCCP with comments relating to NHS CHC on a bespoke basis • Healthwatch Norfolk volunteers are willing to assist NCCP in auditing anonymised complaints, the complaints process and correspondence

Content / activity	Feedback leading to a change by NCCP:
Workshop 3: Reviewing communication on Personal Health Budgets, Information for Parents & Young People, Appeals & Previously Unassessed Periods of Care (PUPoC)	
<ul style="list-style-type: none"> Personal Health Budgets leaflet 	<ul style="list-style-type: none"> Promote the benefits of having a PHB, using real case examples with testimonials from a variety of service users and families Include a reference to wellbeing as part of having health needs met Explain what support is available to those who might want or need it, including when things go wrong
<ul style="list-style-type: none"> Department of Health (DoH) leaflet 'Information for Parents and Young People' 	<ul style="list-style-type: none"> Re-design two in-house versions: one for the parents of young children and the other for young people i.e. teenagers preparing for transition to adult services in a few years Include key sections such as: What is NHS CHC? Who might be eligible? What is the assessment like? What happens next? Remove information about the DoH and CCGs responsibility as this is not helpful to parents Including brief information on the availability of a mediation service with the option to get more information if required
<ul style="list-style-type: none"> Draft Appeals leaflet 	<ul style="list-style-type: none"> Retain this is a good example of format and layout for an in-house leaflet The Frequently Answered Questions section is very informative and could be included in many other information leaflets Substitute the location of the Local Resolution Panel meeting from 'Lakeside 400' to Norwich for simplicity
<ul style="list-style-type: none"> Draft Previously Unassessed Periods of Care (PUPoC) leaflet 	<ul style="list-style-type: none"> Consider whether it is prudent to mention the possibility of a financial refund or payment in this particular leaflet as this might falsely raise a person's expectation prior to the outcome of the process being known Include the term 'Executor' alongside next-of-fin as some individuals may be the Executor of the deceased person's will as opposed to next-of-kind

<ul style="list-style-type: none"> • For all services, replace nationally produced leaflets with NCCP in-house leaflets, since these can be bespoke, are much more user-friendly and locally tailored • Add a date and version number, page numbers and the InTran to each • Where information on how to make a complaint is included, include a description of the options for making a complaint e.g. in writing by email or post, or by calling a number, to ensure equity for people who aren't able to write 	
Content / activity	Feedback leading to a change by NCCP:
Workshop 4: Case Management, Funded Nursing Care, Alternative Care Provision	
Reviewing Role of the CHC Practitioner leaflet	Workshop 4 held 29 th November 2018 Outcomes to be confirmed
Reviewing Funded Nursing Care leaflet	
Information and discussion on alternative / respite care provision if appropriate	

3. Feedback from volunteers with lived experience as carers and next-of-kin contributing to this work.

- *Jill Shattock and her team explain issues so clearly and professionally, which was extremely informative and could be valuable to other families. Along with the patient information leaflet, could there be some kind of audio recording or short film giving a brief explain of NHS continuing healthcare, personal health budgets, funded nursing care and so on, on the Norfolk Continuing Care Partnership website?*
- *Norfolk Continuing Care Partnership have been really cooperative. They've brought the most appropriate people to the meeting- those from the frontline where good communication is most effective - to make the meetings as productive as possible. We've also learnt a huge amount from them so we're now in a better position to give other people, such as the North Norfolk Community Engagement Panel, better quality information about continuing care.*
- *A very positive experience. We've worked in a collaborative manner.*

4. Further points noted during this work

In the course of the discussions, people with lived experience raised a number of additional queries and concerns which are described below. These are for Healthwatch Norfolk, NCCP, CCGs, Norfolk County Council and other partners to address in future.

Awareness raising and accurate information for the general public in Norfolk:

- There is a need to a **communications boost** about NHS CHC: there is more to do to raise awareness and understanding of NHS CHC, what to expect, the process and where to get information and advice (or advocacy).

- Many carers and families are **not aware there can be expenses** associated with care provided through Norfolk County Council's adult social care services e.g. for administration costs for closing down an account, or for interest that has accumulated on payments pending.

Variation between Norfolk's Clinical Commissioning Groups:

- Norfolk has five Clinical Commissioning Groups and we understand as that four of the five commission NHS CHC collaboratively. Unless all CCGs are aligning their NHS CHC policies and commissioning specifications, patients in Norfolk could experience variable service provision.

Training and support for those referring:

- Who ensures there is **training and support** for those individuals who will be making referrals whether that be GPs, Community Nurses, Practice Nurses, Occupational Therapists and especially those in supporting roles e.g. Healthcare Practitioners, care home staff etc?
- Healthwatch Norfolk could ask staff about their knowledge, training and confidence on making an NHS CHC referral during **Enter & View** visits in care homes.

Integrated budgets for integrated care:

- Can we voice our support for integrated commissioning and **integrated budgets / funds** for NHS CHC as means to avoid patients and families becoming immobilised in the process whilst health and social care cannot agree on who should pay?

'Top-Up' fees:

- Some families are asked to pay 'top-up fees' (over and above Funded Nursing Care or CHC) to a care or nursing home; can we encourage people to query what these fees are for, before paying them and how they can get advice on 'top-up fees'?
- Healthwatch Norfolk could ask family members and carers about 'additional charges' for lifestyle and wellbeing expenditure e.g. toiletries, hairdressing, chiropody and access to activities and entertainment etc during **Enter & View** visits in care homes.

Good care in the community:

- Many people are not eligible for NHS CHC however this does not mean they cannot get great care in the community. Community services can provide good ongoing care and support but need to be sufficiently funded to do so.