West Norfolk

Continuing Health Care Innovation

Summary Evaluation Report

November 2016

Partnership organisations participating include:

1. What is the innovative change about?

The subject of this innovation is NHS Continuing Health Care (CHC), which is the name given to a package of care arranged and funded by the NHS when a person aged 18 or over is identified as having a "primary health need." The National CHC Framework[1], a complicated area of health policy requiring professionals to interpret a detailed matrix of criteria refined by legal tests developed through case law, determines what constitutes a primary health need. People considered under the National CHC Framework have some of the most complex, unpredictable and variable health and social care needs and this naturally has a significant impact on them and their families. In addition to this, they are required to undergo a lengthy and detailed CHC assessment process to determine whether their needs are 'health' or 'social' related, which can be extremely stressful.

The particular focus of this project is the impact of the CHC assessment process, both on the individual's experience of care and on the health and social economy. It is well established that CHC is the subject of high numbers of complaints to the NHS and an area of care with rising costs to the state due to the ageing population[2]. There is a wide body of research into the costs of care for the increasingly elderly UK population and the pressure this will create for both health and social care in the next decade [2, 3,4,5,6]. Some reports, such as the Barker Report[3] have made recommendations about how to fund this care in future but at present, there is no fundamental change in the NHS and Social Care funding mechanism proposed. There is therefore a need for local health and social care economies to come up with cost-effective solutions that meet the increasing care needs of their population.

Research on the specific topic of CHC assessment is sparse and it is an area of political sensitivity, being the subject of numerous legal challenges to the NHS where patients and families have appealed against the outcome of their assessment. A multitude of NHS information guides are available online as well as literature offering support such as appeals advice from various private and voluntary agencies and this has proliferated over the last few years. Complaints and NHS Ombudsmen appeals often relate to CHC, with families reporting dissatisfaction with their experience of the assessment process[7]. This has had an

impact on the development of the NHS Guidance on the subject, with several reviews and revisions of the CHC Framework over the last decade.

CHC can be simplistically defined as a two-stage process: the assessment of needs and arrangement of a care package if the assessment leads to a positive eligibility decision. The CHC assessment process can take place in an acute hospital prior to discharge, a community facility or where people reside. National policy places a duty on Trusts providing care to determine whether people need CHC support, however, there is emerging evidence indicating that a hospital is not an appropriate place to carry out CHC assessments. It is recognised in the National CHC Framework that conducting the CHC assessment in hospital at a time when patients often have the potential for significant recovery, makes it an unreliable measure of on-going support needs. It also puts a delay in the discharge process, for a group of patients that are vulnerable to hospital complications when they should be moved to a more appropriate setting to complete their rehabilitation.

This is an area of continuous exploration and many pilots have been carried out to improve the discharge assessment process. These types of initiatives come under the umbrella term 'discharge to assess' with the aim to facilitate early hospital discharge, and more precisely for CHC patients, to provide 'placement without prejudice' before the CHC status is known. The evidence as to whether these initiatives work is mixed, partly due to the heterogeneity of outcomes measured, variability in methodological rigour and the quality of data collected. Many of these schemes come under the national 'Integration Pioneer' programme, established by NHS England to generate and test grass-roots innovative schemes that enhance integrated care. West Norfolk is one the Integration Pioneer sites and the project has been actively supported by the national Integration Pioneer team

The project aimed to find a more efficient and economically viable hospital discharge CHC assessment pathway, leading to satisfactory outcomes for patients, families and all related parties involved in the process. The intervention tested has 3 elements; the '5Q Care Test', a new CHC pathway and an integrated CHC checklist and full assessment post-discharge. The question being tested by West Norfolk was 'Is the new CHC intervention cost-effective and does it lead to improved outcomes for family and patients?' The project aimed to answer the question by gathering a mix of quantitative and qualitative data following the

introduction of the change in CHC pathway. Quantitative techniques were used to test the economic viability of the intervention while qualitative research methods were used to determine whether the outcomes for patients and their families were met.

2. What did the change involve and why was it necessary?

The national NHS CHC assessment process has two stages: a checklist carried out to see if the patient qualifies for a full assessment, followed by a full CHC assessment if indicated.

Historically, there have been wide variations in the interpretation and application of the CHC assessment process[7] that result in subjective decision-making, which raises expectations for the people receiving care and sometimes has to be reversed at the first review after three months, thereby creating high numbers of appeals and complaints. It is well established that hospital stays can be harmful to frail elderly people in terms of loss of motor skills, cognitive impairment and risk of falls and infections.[8, 9.] If the protracted and lengthy assessment for CHC eligibility takes place in an acute setting, the journey and the outcomes for the patients are likely to be suboptimal, resulting in patients and families experiencing often considerable delays to hospital discharge, waiting for information about where they will be cared for and who will be paying for the care and this had been causing considerable distress in some patients in West Norfolk. Guidance in the National CHC Framework[1] states (page 24):

> *"It is difficult to make an accurate assessment of an individual's needs while they are in an acute services environment."*
>
> *"In such situations, assessment of eligibility for NHS continuing healthcare should usually be deferred until an accurate assessment of future needs can be made."*

In 2014, Dame Kate Barker was commissioned by the King's Fund to review the issues of inequality in funding for health and social care and to explore mechanisms to address this. The findings of the final report[2] included:

- **A lack of alignment in entitlements to health and social care.** The NHS remains largely free at the point of use. Social care is both heavily needs- and means-tested. As these entitlements stand they create inequalities that the commission believes are profoundly unjust.

- **A lack of alignment in funding streams.** The NHS, broadly speaking, is paid for out of general taxation and operates within a ring-fenced budget. Social care is paid for either privately or from non-ring-fenced local authority budgets. Councils retain considerable discretion over how much is actually spent. Who pays for what is a source of constant friction between the NHS and social care, with enormous and distressing impacts on the patients, users and carers caught between the two.
- **A lack of alignment in organisation**, with health and social care commissioned separately.

To tackle these three structural flaws, the report argued that England should move over time to a single, ring-fenced budget for health and social care that is singly commissioned.

National statistics on CHC provide a picture of high variability in process and costs associated with reliable, consistent application of the process. The 'Failing to Care' report from the All Parliamentary Group on Parkinson's[7] found that:

> *"All of the health and social care professionals we spoke to admitted the system is so complex they have difficulty following the correct process"*
>
> "*in 21 per cent of cases examined, there were clear examples of existing national guidance not being followed either in the length of assessment or in how the decision is made, with no repercussions for breaching these guidelines"*

The report made robust recommendations to NHS England to improve the quality, fairness and transparency of the entire CHC process.

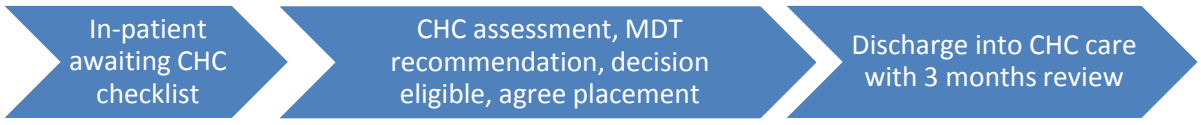
3. The 'pre-pilot' situation in West Norfolk

Across the county of Norfolk approximately 953 people are eligible for NHS continuing healthcare at any one time, currently costing approximately £55,227,848 per annum. This is a disproportionately high cost for the population size and is due in part to the higher than England average of elderly people. West Norfolk CCG has a registered population of 170,270 people, with a rapidly ageing population (the second highest population of people over 65 of any CCG in England), estimated to experience an 8% growth in the next 5 years (ONS,

2012)[10]. West Norfolk recorded a total of 209 people currently CHC eligible during the last week of 2015, just before the new CHC pathway was introduced.

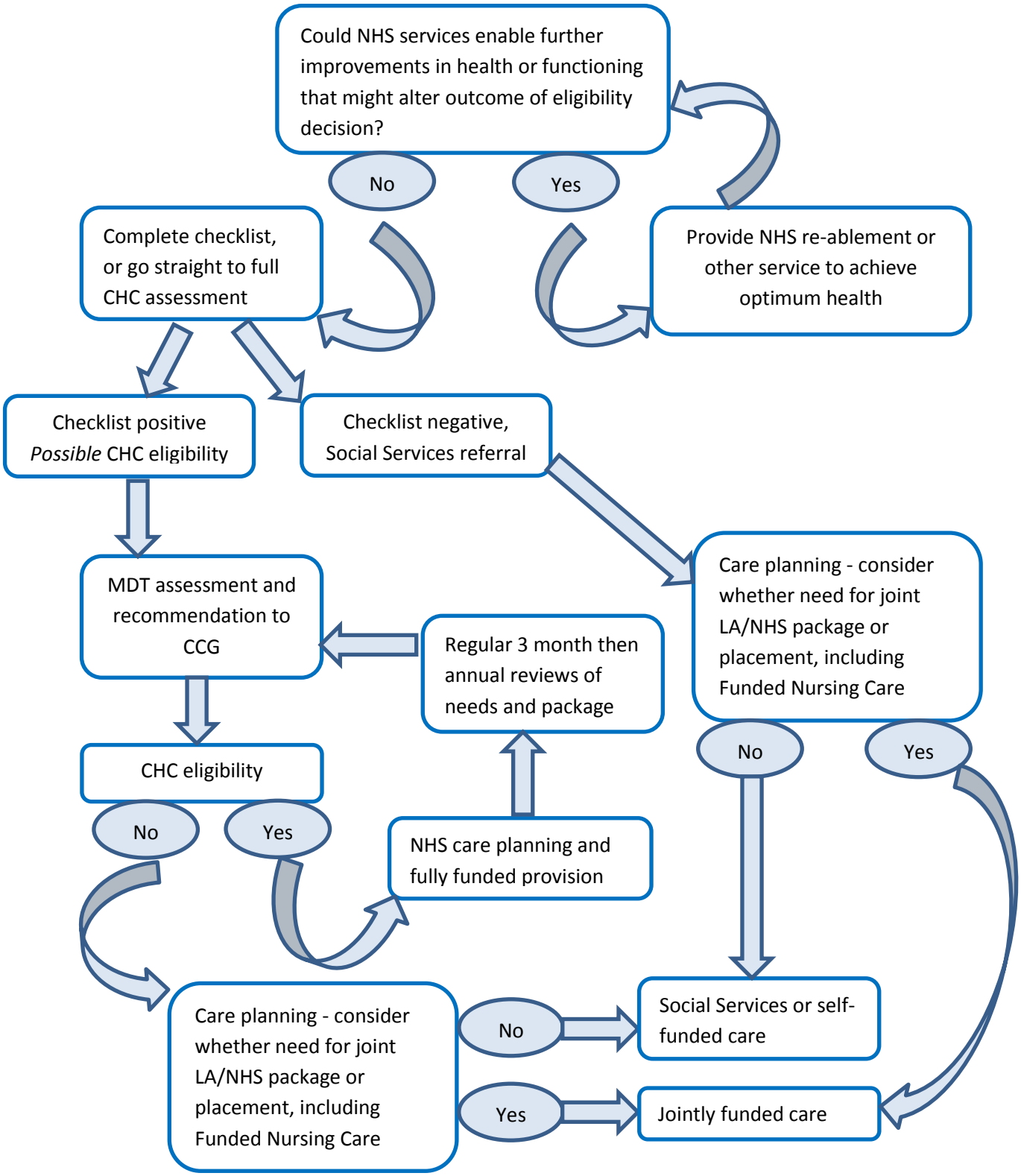
As the main provider of acute services in the West Norfolk area, The Queen Elizabeth Hospital (QEH) provides approximately 450 overnight beds and 115 day beds. During the calendar year 2015 there were 300 West Norfolk patients who had a CHC checklist in the QEH. In this study we followed the journey of these patients during 2015 and contrasted it with 'the intervention' or new pathway. During the fiscal year 2015/16, the QEH reported 83,300 discharges. Up to the 31st December 2015, CHC checklists and assessments were conducted in the hospital. This involved health and social staff making individual assessments, completing the necessary assessment documentation and holding a joint meeting to include the family before making a recommendation for CHC funding or not, as illustrated in Figure 1.

Figure 1: NHS CHC previous acute trust pathway



In the above pathway, patients are discharged from hospital as CHC eligible and are provided with a CHC care package with an NHS funding commitment until the first review at 3 months. On this pathway, any of those patients who might have been prematurely awarded CHC because they had not completed their recovery, would not be re-assessed until 3 months following discharge. If at this point they became ineligible, there was potential considerable disruption, as they would be in a care setting based on being CHC eligible. The transition from CHC eligible to ineligible is often fraught as it involves a transfer of funding responsibility which may necessitate a change in accommodation. The decision-making tree associated with this pathway is illustrated in the flow diagram in Figure 2 below.

Figure 2: Patients with complex care needs – Original decision-tree



4. What was expected to happen as a result of the change?

The expected outcome was that the removal the CHC assessment (and checklist) from the acute hospital, conducting it instead in the community once the patient has reached their optimum recovery from the acute period of illness, would translate into the following benefits:

I. Quicker discharge from hospital, thereby reducing risks associated with hospital admissions such as infections and falls and improved hospital operational flow, measured by reduced 'excess bed days';
II. A more reliable indication of long term care needs, that efficiently filters those patients who do not need a checklist. Thus long term health care needs are reflected more accurately.
III. A reduction in CHC cases due to improved recovery and independence as discharge fore-shortened the motor and cognitive skills decline associated with hospital admission in the elderly;
IV. A significant reduction in bureaucracy and workload for discharge nursing teams;
V. A higher satisfaction level among patients and families of the CHC assessment process.

The expected result was therefore that there would be an improved patient experience of hospital discharge as well as economic benefits to the health and social system.

Ethical approval was not sought for this study as it comes under the category of a small local service evaluation and therefore an application to the research ethics committee is not required. The intervention was universal, no patients were selected as 'in' or 'out' of the pathway and the study was simply an audit or evaluation comparing the evidence before and after the change.

4.1 Distinction between 'Nursing' and 'Care'

Currently NHS nursing is free, social care is mean-tested. During the early exploratory work in this study, there was much debate between health and social care partners about the distinction between nursing and care needs. Frustration was expressed about the difficulty

in defining this and the CHC checklist is most commonly used when there is any doubt. However, this often results in an over-zealous use of the checklist, which then commits staff to a statutory pathway which includes a full CHC assessment. The high rate of negative CHC eligibility following a positive checklist (90% in West Norfolk before the study), illustrates that people were inappropriately entering the pathway. A discussion about how to assist health and social care practitioners in judging who should have a CHC checklist was therefore initiated and explored at a 'co-design' event held in November 2015.

The following statements were tested during the design phase:

1. The difference in personal care provided by a social care worker and a health care assistant relates mainly to their care model of 'promoting independence' versus 'treating', as opposed to their qualifications and skills
2. Therefore, if care can be met by either of these care workers, the patients could be said to have the same level of need.
3. 'Care' (as opposed to 'nursing') is that which could be given by a competent relative at home, with some instruction and support.
4. Patients who need the constant attendance and frequent intervention of a registered nurse, in excess of that provided by the periodic community nursing service, need 'nursing care'.
5. 'Nursing' is that which could not reasonably be expected to be given by a relative because it involves making judgements, interventions and decisions based on nursing knowledge that a lay person could not be expected to have.
6. This includes mental health distress and extreme behaviour.
7. Where families need extra hours of care and support, but that care is at a level they could provide if there were a wide enough family network to cover, it is not 'nursing'.

4.2 Outcomes

Having debated these statements fully in a multi-organisational forum, there was agreement that they were valid and provided a basis to assist judgement about which people should have a CHC checklist. As a result, a new dependency test called the '5Q Care Test' was developed, whereby people's needs are classified as 'nursing' or 'care' (see

appendix 1). This test was used to determine which patients should receive a CHC checklist assessment once they have settled in the community and which should immediately transfer to Social Services due to their level of care required. It is important to state that this test does not in any way replace the CHC checklist or CHC assessment and does not alter patients' rights to request a CHC assessment due to a change in their needs. The test was developed to assist practitioners to make a judgement about whether it is appropriate to initiate these assessments at a given point in time, determined by the level of care required.

5. What does the new pathway look like?

The new CHC pathway from January 1st 2016

Following the 'co-design' event in November 2015, materials were collaboratively developed and approved by a joint health and social care committee. These included the 5Q care dependency test, a new pathway for hospital discharge and information for staff, patients and care homes. The hospital discharge liaison nurses ceased all CHC assessments and focussed on placing patients into appropriate community care following application of the new '5Q Care Test'.

This provided two routes out of hospital:

a) '5Q Care Test' determines the patient has social care needs on discharge, which could be met at home or in a residential care home – hospital raises an assessment notice and discharge notice to social care. Any nursing needs can be met by the community nursing service.
b) '5Q Care Test' determines the patient has nursing care needs which cannot be met by Social Services plus community nursing – patient discharged to an NHS funded community care setting appropriate to their level of need.

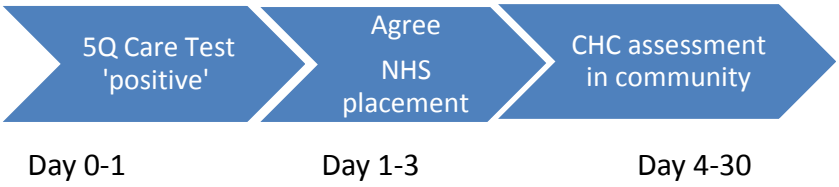
For those patients discharged to a health funded placement, a comprehensive, multi-disciplinary CHC checklist is then conducted in the community setting by the CHC assessor along with a social worker, the care provider, the patient and family. If the checklist is positive, the evidence is used to populate the full 'DST' framework to complete a full CHC assessment there and then, with all parties involved and agreeing the recommendation.

Theoretically, by 28 days post-discharge the full CHC assessments will more accurately predict on-going care needs, thereby avoiding the disappointment experienced by patients and families when a 3 month package is ended once the patient's condition has improved.

It was agreed that if any of the people discharged to social care support subsequently triggered a CHC assessment within 28 days and were found to be eligible, the NHS would repay the family or Social Services the costs of care for the month after discharge. If they become eligible at a later date, they would be treated as any Social Care placement that develops CHC eligibility.

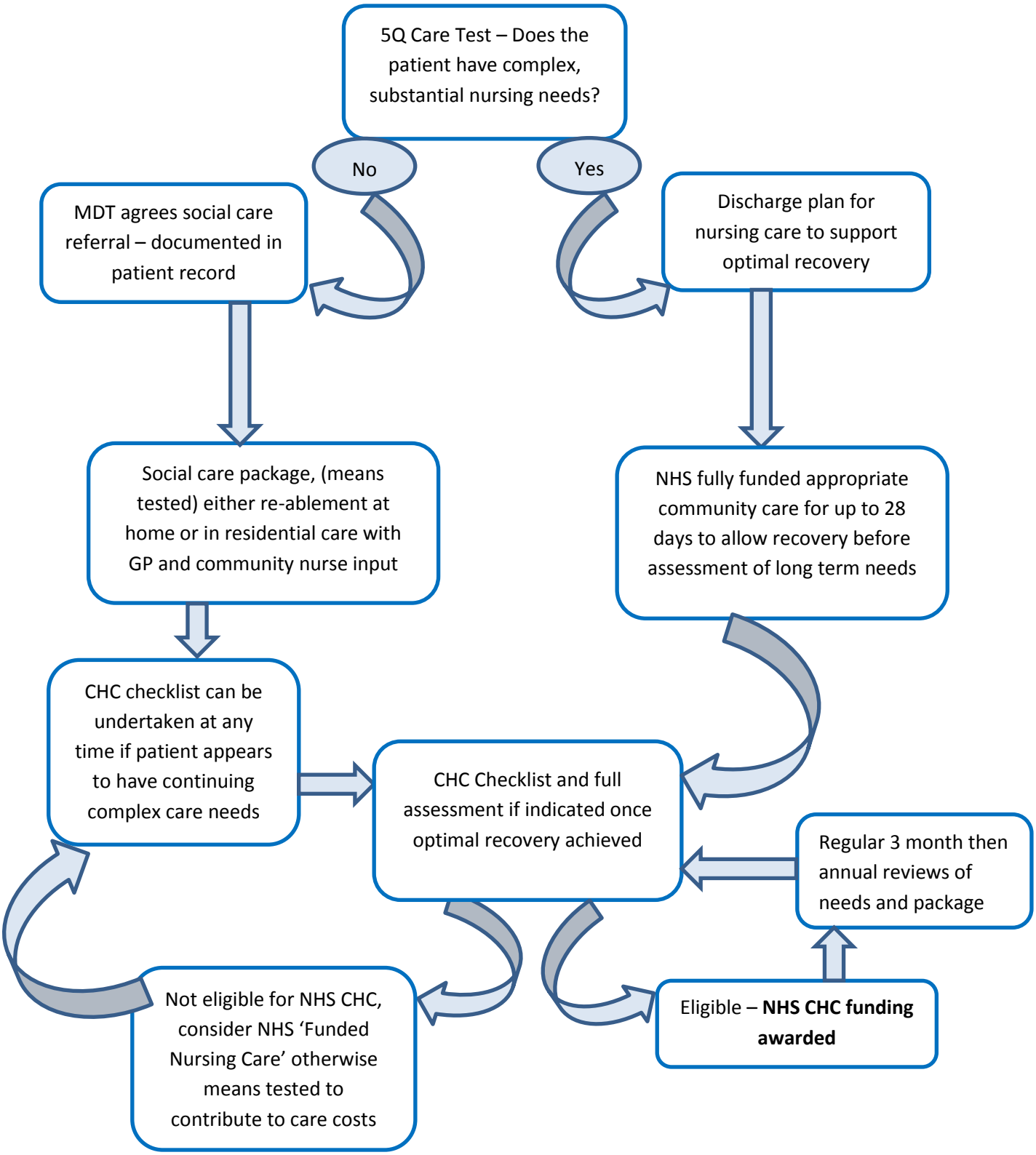
The pathway is illustrated in Figure 3 below.

Figure 3: NHS CHC new acute pathway



The new CHC hospital discharge decision-making tree which supports this pathway is illustrated in the flowchart at Figure 4.

Figure 4: West Norfolk Complex Care needs – New discharge decision making tree



6. What happened as a result of the new pathway?

Evidence from this study suggests that the introduction of the new CHC pathway is cost-effective and has improved outcomes for family and patients.

Evidence from the health economic impact analysis suggests that there is a £562k statistically significant ($p < .001$) cost saving as a result of the intervention. This figure reflects the health cost difference for the period January to July incurred from patients entering the intervention via QEH admission. The major component leading to the cost difference was the substantial decrease in CHC positive eligibility decisions since patients were quickly referred to suitable services as a result of the intervention.

Zero Delayed Transfers of Care from hospital due to CHC funding decisions were reported in this period as well as reductions in excess bed days thus relieving operational hospital pressures that translated into system operational efficiencies. A reported 81% reduction of checklists, from 178 to 34, was also noted.

The average Social Care costs associated with the intervention have been estimated at £983k based on information provided by Social Services. Due to the lack of baseline data, it was not possible to calculate the cost of the old pathway; however, finance scrutiny and activity data comparisons between the same months in 2015 suggests that the intervention did not create an increase in social services referrals or have an adversely material impact on social care costs. It is important to stress that the savings realised through the pilot have been achieved through more efficient working that reduces length of hospital stay and reduces the complexity of CHC packages required due to earlier discharge and optimal recovery. They are therefore 'real' reductions in health care costs. There is not sufficient data to determine whether there are any consequences for social care costs but at a macro-level there was no evidence of an increase.

7. What did patients and staff think?

Qualitative data were collected through interviews. It was important to ascertain the experience of those administering the new CHC pathway and those who were undergoing it,

in order to determine whether there were any perceived negative effects that should be considered along with the quantitative results. Since the original reason for reforming the pathway came from negative feedback from families and staff, it was important to document any impact, positive or negative, that the new pathway might have. Stakeholder and user experience contributes to service quality improvement[11] and is a key component when evaluating a quality improvement initiative. West Norfolk CCG commissioned Healthwatch Norfolk to capture the views and experiences of patients, family carers and health and social care professionals regarding the intervention pathway, to ensure impartiality and to give staff freedom to express their views without reserve. Some of these staff had been in their role before the pathway commenced, others had not. All staff were free to refuse to take part and the results were presented in an aggregated anonymous format, to reduce the likelihood of attribution of remarks to an individual.

The CHC Assessors and hospital based social workers sent 26 patient packs by post on behalf of Healthwatch, from which two responses were received. One telephone interview with the next-of-kin of a person on the CHC health pathway was conducted and transcribed to a clean verbatim text. A second response received indicated that the next-of-kin declined to be interviewed as they felt they could not adequately represent the patient. No further consent forms were received from patients or family members. Healthwatch chose not to include the single interview in the evaluation; this was not in any way to diminish the importance of this individual's experience but it could not be viewed as a representative experience of 26 patients (or families). The exclusion was purely to avoid bias.

The views of staff were mixed, with hospital nurses being the most enthusiastic about the new pathway and social workers the least. Care Homes felt they had been kept informed and involved but had not felt they had much influence on the process. Staff also had varying views about how patients felt about the pathway. Hospital staff reported that patients and families accepted the fact that CHC assessments were no longer carried out in hospital, that the discharge process had improved and incidents resulting in families becoming upset or angry had reduced. Social care staff expressed a view that families and patients on the social care pathway were sometimes not well informed about the CHC

process, suggesting that perhaps the pathway had made them less aware of their right to an assessment, despite having been given an information leaflet by the discharge nursing team.

The pathway was clearly a significant change for staff to accommodate and as expected there was a spectrum of responses, ranging from resistance and resignation, to embracing the change. This provides extremely valuable data which helps to inform future CHC reform by illustrating the tensions and perceptions of different professional groups. CHC is a fraught topic where any proposals are likely to be met with a degree of suspicion and wariness. Understanding where these concerns stem from and addressing them early in the process is essential for success.

8. Next steps

Evidence from this study suggests that the introduction of the new CHC pathway is cost-effective and has improved outcomes for family and patients. The hypothesis posed has been supported namely that removing the CHC checklists and assessments from the hospital setting, replacing them with a test which filters those that should have a CHC assessment into a health funded pathway, and conducting the assessment in the community once people have regained optimum recovery did produce benefits in terms of patient experience and cost-efficiencies. No complaints were received by either health or social care related to CHC during the study period.

The CCG and Local Authority have agreed that the pathway will continue, with a modification following the evaluation whereby the 5Q Care Test is used by the discharge nurses to identify which patients they need to have a conversation with Social Services about but not used as the evidence for determining which discharge pathway they should follow. The health and social care Multi-disciplinary Team (MDT) will conduct a bed-side review of the patient's needs and make a joint decision about whether they should be accepted as a social care referral and this will then be documented in the patient record. There will also be more robust social care data collected by the Local Authority, to enable a 'whole system' as opposed to just NHS economic impact analysis.

The results from this local study may be replicated in other health and care economies wishing to address quality and economic problems in their CHC service and this would provide further data about the effectiveness of the model. The economic impact analysis framework described in the study provides a range of financial savings with a probability value that may be applied to different settings.

Careful preparation, stakeholder engagement and collection of high quality data for establishing a baseline and capturing any impact specific to the intervention are all essential prior to successful implementation of such an initiative and the learning from this study provides some insight into the importance of addressing these.

The recommendations from this study are:

1. The reliability of the 5Q Care Test in determining accurately which patients should have a CHC check-list should be tested in a wider population and in the community setting
2. The benefits demonstrated in this study need confirming in different health and social care economies
3. Community capacity to undertake CHC assessments should be enhanced to allow for the transfer of this function out of hospitals
4. Health and Social Care partners should negotiate the terms of any similar pilot with a written Memorandum of Understanding to ensure all parties fully understand and agree to the process, particularly including collecting high quality data.

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14. Sheffield Discharge to Assess frailty unit - http://www.health.org.uk/newsletter/%E2%80%98discharge-assess%E2%80%99-sheffield-frailty-unit
15. South Gloucester and Bristol Discharge to Assess - http://www.nhs.uk/NHSEngland/keogh-review/Documents/quick-guides/background-docs/50-D2A-SGloucBristol.pdf
16. Emergency Care Improvement Programme at http://www.ecip.nhs.uk/

Appendix 1

Patient's NHS Number:
GP Surgery:

NHS
West Norfolk
Clinical Commissioning Group

Care and Nursing needs assessment – '5Q Care Test'

Continuing Health Care (CHC) assessments are no longer carried out in hospital. There is still a need to determine whether patients who are ready for discharge have 'care' or 'nursing' needs in order to provide the appropriate health or social care support. This assessment tool is to be used to support the decision and must be approved by the Discharge Planning Nurse Lead.

(1) Could the patient's care be given by a competent relative at home, with some instruction and support?
YES/NO

Describe your evidence for this:

(2) Could the patient's care be provided in a residential care home with community nursing support?
YES/NO

Describe your evidence for this:

(3) Is intervention from a nurse needed because the care required by the patient involves making judgements and decisions based on **clinical knowledge** that a carer could not be expected to have?
YES/NO

Describe your evidence for this:

(4) Is close supervision by a nurse needed due to the **risk of patient harm** if not provided? (This includes severe mental distress and extreme behaviour.)
YES/NO

Describe your evidence for this:

(5) Is a nurse is required to supervise, train and delegate the care of a patient, whilst **maintaining accountability** for the delivery of that care by a person they deem competent?
YES/NO

Describe your evidence for this:

Can care be met by social care with community nursing support? **YES/NO**
If **YES**, refer to social work team
If **NO**, refer to an NHS service below

Referral made to:
(Delete those that do not apply)

Social work team	
Virtual Ward (home)	
Rehabilitation Unit	Location:
Community Hospital Bed	Location:
Nursing Home	Location:

Confirm patient/family has been informed that NHS funding is for 28 days only unless CHC eligible?
Patient and Family information leaflet given and discussed **YES/NO**

Next of Kin: NAME CONTACT TEL. NO.

SIGNED _____ PRINT NAME DATE
(ASSESSOR)

SIGNED _____ PRINT NAME DATE
(DISCHARGE PLANNING NURSE LEAD)