Torrington Community Cares: Meeting local needs
Staff and stakeholder engagement and involvement report

Appendix 5
Patient Story report

Summer 2014

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www.torringtoncares.co.uk

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1. Introduction

As part of the engagement and involvement exercise we wanted to ensure that we were hearing the voices of a wide range of people, and not only those who were able to attend public meetings or drop in sessions. Key stakeholders of this project, and those for whom the pilot was having a direct and immediate impact on was of course the patients receiving the new enhanced model of care.

Patient experience forms an essential part of patient care, and there is considerable evidence to suggest that positive patient experience correlates with positive clinical outcomes. Quantitative data was gained from the patients via patient surveys and qualitative data was gained via these patient stories.

Patient stories are powerful tools which, beyond the figures and statistics offer a deep insight into how it really feels to receive a certain type of care. In addition to feeding into the evaluation of the pilot, it was hoped that these stories would help increase the understanding of the new model of care, and how it might feel to the public should they be in need of this type of care.

Six stories were gathered in total, from people receiving different aspects of the service.

In order to support the wider accessibility of this work, three of these stories were also made into a film and can be found on the website at www.torringtoncares.co.uk.

2. The process

1. **Interviewer**: Engagement and Involvement Lead for the Northern Devon Healthcare NHS Trust

   Reasons:

   - Relevant skills and experience for carrying out patient interviews
   - Has been DBS checked
   - Works in line with the Trust lone working policy
   - Was not the care giver for any of the patients

2. **Identification of patients**

   District Nursing: Patients were contacted at random and consent gained for the interviewer to make contact and arrange interview.

   Parish Nursing: This individual came forward to offer their perspective as she lives alone and recovered from surgery with the support of a parish nurse.

   Rapid Response: All patients who had received the rapid response service during the pilot were contacted and consent was requested for the interviewer to contact the patient. Of the 13 who were contacted:

   - 4 gave consent and were contacted – on visiting one of these was not appropriate due to cognitive impairment
   - 3 did not consent
   - 6 were not contacted due to suitability or lack of resources (eg had dementia or unable to answer the phone)

3. **The interviews**

   Interviews were arranged at various times suitable for the patients and carried out at the patient's home. The interviews varied in length depending on the patients and the experiences they had had. Every interview was recorded. The experience was then written up as a patient story by the

Engagement and Involvement Lead

4. Sign-off and Validation

In order to ensure transparency, it was important that there was a robust validation process to these stories. Stories were signed off firstly by the patient and then independently validated.

The patients sign-off

Once the story had been written up, it was sent to the patient with a consent form (see appendix i). The consent form requested confirmation from the patient that the write up was a true reflection of their experience, and asked whether the patient wished to be anonymous in their account.

Patients were given time to read through their accounts before the interviewer re-visited them to collect the consent document. Any changes requested were duly and noted.

Independent validation

To further ensure scrutiny, and mitigate from potential queries with regards to bias during the interview such as leading questions, the patient stories were also validated by a member of Healthwatch.

The Healthwatch representative was given the written story, already signed off by the patient to read through and then compare with the interview by listening to the recording. They then signed the independent validation form (appendix ii). The Healthwatch representative also signed a confidentiality statement in accordance with the patient consent form.

Patient Story 1: Averill and Dennis, District Nursing

Averill and Dennis live together in their home. 18 months ago, Averill was diagnosed with terminal bone marrow cancer; Dennis is now her primary carer. Averill has a complicated medication regime that at times can make her feel very unwell. Her and Dennis are supported by the district nurses who come and visit them both at home.

“I’m not feeling very well at the moment” Averill tells us. “I keep feeling very faint because of the drugs but I know that the nurse is coming in a couple of days. Now, please can you put this in capitals?” she asks “ALL OF THE NURSES HAVE BEEN WONDERFUL. They are just so so caring – it’s like they’ve know us for years. I don’t know how I can say it in any other way”

“I’ve never come across a group of people that tend us so well. It’s really comforting”.

Averill and Dennis explain that the nurses come in to take Averill’s blood so that it can be monitored and her treatment can be arranged accordingly. “They are always there to answer any questions I have and I really feel I can talk to them. When you’ve got what I’ve got, it’s scary, its just terribly scary. They tell me as much as they can – but they don’t know just how long it will be. Talking things through really helps though”

Dennis is Averill’s main carer “we’ve never been apart -he tends to everything I need” says Averill. Dennis adds “we do everything together – we always have! I bath her and do her hair – we’re getting by. When Averill finishes a round of treatment she can get very poorly and I have to monitor whether she needs to go into hospital – she copes with it very well really.”

“I used to have a wonderful person come and see me from the hospice as well. She came every week and was fantastic, she knew that I was frightened and talking to her made such a difference. She retired though and the other person who comes now is only part time so it is not as often. She is lovely but I would like it if she came more often – you can’t have everything though can you.”

Averill explains why she wants to tell us her story, “I want to help other people to understand how good the nurses are, how much care they have given to us at home and just how caring they are. You see, you turn the television on and hear such awful things about what is happening to people and you can’t believe it because it is so different here. I can’t tell you how good they have been to me – and to him - they are so

kind. I always want to thank them, but I suppose they get a lot of thank you's!"

Dennis says "It's our 60th Wedding Anniversary this year we've said we'll keep going until then! Averill might need to go into a hospice we think, but we don't know yet. I'm not going to let her go yet – we'll get as far as we can and then work that out when it comes" "He's husband number one!" Says Averill "He is adorable and so so caring!"

That's my daughter up there – ran the Devon Life magazine – she died at aged 32 from cancer. Her children were 8&9 so they were with us for most of the time. Both have gone through University and have good jobs now that they love. You relax when they have got a good job – like they are going to be OK.

Patient Story 2: Sophie, District Nursing

Sophie is 89, she lives alone in her house that her and her husband retired to 30 years ago "It did us just fine and now, well it does me on my own now".

While out in the garden, Sophie hurt her leg on a concrete step. She didn't think much of it at the time and thought it would be OK, but when her carer came round she advised Sophie to seek medical advice about it. "I didn't need to go to hospital or anything, the nurses just came and saw me at home. They come once per week now to re-dress it and it's generally the same person who visits. I can't get about much these days you see so it's so good that the nurses can come and see me at home. I never feel rushed or anything like that, they just stay here for as long as it takes they are very patient!"

Sophie explained that she also has a carer who comes and visits her once per week. This is a private arrangement booked through an agency. This person helps Sophie with her shopping, and can be around whenever Sophie needs any non-medical help. "It works very well" says Sophie.

Sophie explains that she doesn't go out in the garden as much as she used to, "It's not just since my leg, but generally I don't want to push it. I'd absolutely hate it if I had a fall up there and all and sundry had to come rushing over. So I take it steady – that's the best way!"

Sophie tells us that she feels very confident that if anything were to happen such as a fall or if she needed help then she could call the health centre where the nurses are based "I know that they would come if I needed anything – they really are very good – I have no complaints what-so ever"

"There really isn't anything I can think of that could make it better, they are all very competent you know and the whole thing is very organised! They are very good, lovely people" says Sophie. "I couldn't fault them. I don't know how they do it really – visiting all these people – they are so dedicated – we are lucky to have people like them!"

Patient Story 3: Bryan, Rapid Response

Bryan lives on his own at his home in Torrington. He suffers from Chronic Obstructive Pulmonary Disease which can make it difficult for him to breath; this is generally managed with inhalers. In November 2013 Bryan suffered a severe flare up of his condition and became very unwell. "I remember feeling very poorly, I felt dizzy all the time" describes Bryan "I wasn't able to speak very well and my mental and physical processes were in shreds. I couldn't do anything for myself and frankly felt that I was on deaths door." Bryan's daughter contacted his GP and Bryan was referred to the rapid response service. Bryan received twice daily visits from the District Nurses and as his condition improved occupational and physiotherapists also visited to support him with his rehabilitation. Bryan received the rapid response service for 6 weeks.

"My overall reaction to the whole care package and the people who contributed to it was very positive indeed and above my expectations, especially with all the furore there has been about closing down the

beds in the cottage hospital (where I have previously been as a patient). This care package for me was about the most thorough that I could conceivably have expected. There was no need for hospital because I would have just gone through the same processes there as I did here. I really didn't expect it."
"I was bedridden for 3 weeks and all sorts of clinical things had to happen to me all of which were carried out with total respect. I was provided with oxygen to help me with my breathing difficulties and after lying flat for all that time I became very weak. It must have taken a full month before I felt competent to get out of bed and stand up and hobble with the aid of my walking stick to the bath and shower. I was dispirited by it because I didn't feel like I was getting anywhere at all. But I was encouraged by the people who visited me, which was great. They over-came the misery that I was feeling! It took six weeks before I was really ready to face the open air again."

"The only thing I would fault is the lack of coordination between the people who provide the services. I was astonished at how many people were involved with me and found it, and still find it extremely difficult to identify the origins of the various elements of the care package that I received. Of the people who came to see me there are only two that I can recall who were consistent with one another. I had twice daily visits, but I never knew who was going to arrive, at what time or what they were expecting to do. I know that each new person announced who they were and where they came from when they arrived, but my ability to take in that information was very limited because I was not mentally capable of putting it all together – if I had had any sort of Alzheimer's it would have been very confusing."

"The first five or six days were very laborious as I had to dictate the same thing to a different person twice per day! I couldn't quarrel with the intention of this because it was very clear that they were trying to get a clear picture of the condition I was in, and what I was experiencing, but it was frustrating especially as I was feeling pretty awful and the last thing I wanted was to have to be repetitious; it seemed that they were only concerned with their own specialism and did not talk to each other."

"From the point of view of the recipient this is all a bit unnerving. What you need as a receiver of care, in whatever form it takes, is confidence in it, and if you feel that nobody is talking to anybody else it doesn't boost your confidence at all. A lead person would be helpful for the whole process – like a care coordinator, they could leave the patient with a map of who is coming from where and when if possible – it would indicate to the patient who to call at any one stage. I was in no doubt though that if I did need to call, someone would come."

Bryan explains that there were two folders kept at his home that were written in each time someone came to visit him; towards the end of his care plan, anyone who came to see him would read what the previous people had written. "I couldn't fault having this long narrative all about what had happened, but it was never open to me – maybe because I didn't ask."

"That's my over-all impression anyway. No one comes to see me anymore, I am totally discharged! I wouldn't say I feel as strong as I did before this thing hit me, and I do things a little more slowly now and with more care. Nevertheless it all worked and it worked to the time table I was anticipating, and I am back on the job now and doing the things that I enjoy. Personally, in my present and immediate past state I would feel very confident to be treated at home because the people I have been concerned with have been remarkable."

I have to say that nationally the care profession do not get the best kind of treatment so far as Torrington and the NHS in Torrington is concerned. From my experience it is all rubbish as the people I have been concerned with have been remarkable. I didn't appreciate it at all the care I could have at home. The changes I would suggest are about reassurance and how care is delivered, it is not about the level of care.

Patient Story 4: Jenny, Parish Nursing

Jenny lives at home in a very rural part of Greater Torrington; in November 2013, Jenny was diagnosed

with colon cancer, 20 days after she received her diagnosis, Jenny had surgery to remove the tumour. “I was fortunate in that it was a low grade cancer that I had and it hadn’t spread” says Jenny. “I was in hospital for four nights and then I came home”. Next door to Jenny lives Lyn who is a Parish Nurse, with her nursing background Lyn provided Jenny with support at home to help with her recovery.

As well as the support Lyn provided to Jenny when she came home, in her role as Parish Nurse Lyn attended appointments with Jenny prior to her diagnosis and in the build up to surgery. From her nursing background, Lyn was able to answer any questions that Jenny had that she hadn’t thought to ask in the appointment.

Jenny was discharged on a Saturday and returned the following Wednesday to be told the surgery had been a success and all was clear. “One of the nurses who had looked after me when I was in hospital was there when I was at the follow up; she was so excited when I told her the good news. She ran back in the ward and told another young nurse who had looked after me and came back and told me how excited she was! It made us wonder if the nurses ever get the results of people that they have looked after...”

The availability and proximity of Lyn was included in Jenny’s discharge plan “I didn’t even think about what would happen when I came home to be honest; I hadn’t really got that far! But there was never any question about it because Lyn was there to look after me”

“When I first came home I was very sore and I was surprised at how weak I was” explained Jenny. “Lyn would come round first thing in the morning to make sure I was up and that I’d had breakfast. She would then check my dressings, and I’d get dressed. Then I’d have a lie down on the sofa, usually fall asleep, and then lunch would be here!” Being a neighbour, Lyn was able to cook food for Jenny and bring food round to her; this ensured that Jenny was getting the nutrition she needed. Lyn describes that she would also ensure the house was warm enough and there was wood for the wood burner. “As a Parish Nurse we can do things like that, things that are just not possible for District Nurses because they don’t have time, and it’s not what they are there to do”

It was Lyn who first noticed that Jenny was developing an infection in her scar. “It was a Friday” Jenny explains “Lyn said that she thought I should really get it looked at before the weekend, and sure enough when we got to the doctors there was an infection there. I had to go to the surgery to have my dressing changed every day at first, but then because Lyn was around, she was able to change them to save us the journey. I had two weeks of antibiotics as well, but it got better in the end!”

Jenny didn’t receive care from the district nurses, because Lyn was available. Although Parish Nurses do not provide intensive medical care like injections or leg ulcer dressings, they do provide reassurance. From Jenny’s point of view, “Having Lyn around was 100% the reassurance I needed to feel safe. It was so good to know that there was someone there who was trained! It was completely brilliant and it really worked.”

“If Lyn hadn’t been around I would probably have leant quite hard on my family – my sons and their wives. Or, would have needed someone at least 2 or 3 times per day to come and help me – I was very lucky in that Lyn is my neighbour so she just popped in and out. If it hadn’t been for the Parish Nurses I might have gone to the Cottage Hospital, but I much preferred being home – there is nothing like your own bed”

Jenny is now 15 weeks clear of the cancer she suffered from. “Someone getting better isn’t just about the medical side of things” she says “it’s also about how you feel. Having Lyn as a neighbour and Parish Nurse was absolutely brilliant and it helped my recovery no end. I really couldn’t fault it”

Patient Story 5: Joyce, Rapid Response and District Nursing

Joyce lives alone at her home in Dolton; her daughter lives not far from her. Over the last year Joyce has been admitted to both North Devon District and Torrington Hospitals. She has also

received care from the district nurses and rapid response teams at home for various problems relating to retention of urine and bowel obstructions.

Before she was admitted to hospital in March 2012, Joyce had been suffering with urine retention problems. Joyce was then admitted to NDDH with a bowel obstruction as well as retention of urine. After two weeks Joyce was discharged home, but was quickly admitted to Torrington Community Hospital after having a fall. “I think I was discharged too early from NDDH” Joyce says “I’d only been home for one night when I had a fall in the middle of the night. I lay on the floor for two hours before I called my daughter! My daughter called my friend who called the GP and I was admitted there die to acute sciatica because of the fall”

“The care I received at Torrington was excellent. I was in a lot of pain and they were never too busy to help me. Quite honestly I do think that the beds are needed for post-operative care or observations – that is when I was in for. I live on my own you see, and I don’t think I could have had the same level of care at home because I was in such a lot of pain. Luckily Torrington was close for my daughter to visit too – she couldn’t have come to Barnstaple for all that time – it cost her a fortune for the time that I was there.”

After two weeks, Joyce was discharged home from Torrington as an outpatient for her initial condition, and between February and December she was supported at home with input from the GP and district nurses. “During this time I went into retention twice – I found it very hard to cope with, and both times I had to be catheterised. Someone even came over to try and teach me how to self-catheterise, but it wasn’t possible, so after my last admission in December 2013 I came out of hospital with a permanent catheter. The District Nurses were brilliant though, so supportive, so good. Now they come every three months to change my catheter, but I know that I can call them whenever.”

In December 2013 Joyce became very unwell again with her condition. “The OT team came over when I was in a lot of pain and assessed my home. While they were here they made arrangements for the home care team to come in to keep me at home. But over the next couple of hours I was admitted to NDDH so I had to call and cancel all the home care they had arranged. When I was discharged from hospital they were supposed to come in but nobody turned up. I don’t know why – maybe because it was Christmas and they were busy. It was OK because I went to my daughter for Christmas and boxing day, and then I was Ok, I just managed on my own.”

Joyce is currently being seen as an outpatient and it is likely that she will require further surgery which she has been told will be quite a big operation. “I don’t know what the aftercare will be if I do have the surgery” Joyce says, “The older you get the longer it takes to recover; I don’t know if I would be able to recover at home, I do have a lot of friends in the village, but they all lead their own lives. The District Nurses are all very nice, but they don’t hang around, because they are busy. My daughter wouldn’t be able to live here, but she would come up. I think she was under the impression that if I did have the surgery I might go to Torrington afterwards”

“It would be good if there were other services at the hospital though. In a village like this where there are young children, how do people cope with going to Barnstaple? It’s easy to get to Torrington. It’s the way forward – that’s the thing isn’t it. I think people worry about if they would have to pay for care as well. I have received good care from the district nurses too. Nothing is too much trouble and if there has been a problem they have always come out straight away. They were fantastic.”

Patient Story 6: Doris and Graeme, Rapid Response

Graeme is the primary carer for his mum Doris; they live in her home in Torrington. About four weeks ago, Doris was discharged from Northern Devon District Hospital (NDDH) in Barnstaple where she had been for about two or three months.

In October 2013 Doris was admitted to Torrington Community Hospital. Graeme explains what happened: “The doctor came over and he didn’t really want her to go anywhere! He said he didn’t even know if Torrington was open. I told him that it was and in the end he let her go there. She was in there on her own for a couple of weeks and then someone else came in as well. I think he didn’t want her or anyone else to go in there so they could say that when the beds were open they weren’t being used.”

Doris was discharged home from Torrington but after being at home for about a week she became very unwell and had to be admitted to NDDH. Graeme says that “It took about six to seven weeks at NDDH before she became well enough to be discharged. At this point she should have come back to Torrington, but the beds had closed then. They kept asking if she could go to Holsworthy because they needed the beds, but there is no way I could have got there, it’s too far! Bideford was the next closest one, but that was full so she couldn’t go there, so then they talked about South Molton and I told them that was even worse than Holsworthy! So she ended up staying in NDDH until she was really better to come home. This was made longer because there kept being sickness bugs going around the ward, it happened about two or three times when mum was there. This might not have happened if she’d come to Torrington and she might have ended up being home quicker.”

Graeme explains what the impact was of his mum being at NDDH for a long period of time. “I only get carers allowance” he explained “so it was a real struggle to have to get to Barnstaple every day. I made sure that I went every day; I wasn’t going to leave her there all alone. But nobody cares about that. Then you have to pay for parking, and it’s also difficult to find a place to park. My uncle who is 91 lives in Torrington as well. When mother was in the Cottage hospital he used to sometimes get a cab to come and see her, but there was no way he was able to do that when she was in Barnstaple.”

The possibility of receiving care at home was never discussed with Graeme and Doris. “We have carers who come in” says Graeme “They come in four times per day now to help her go to the toilet and things. I think that she would have been too poorly to go home. It’s different in the hospital, because you have nurses popping in and out all the time – when it was just her in Torrington she had all the attention to herself! They would also get her to walk from her bed to the tv room so she was getting exercise.”

“When mum came home, the physio came in for the first week; maybe two or three times. Then they told me there wasn’t any funding for any more and we haven’t see anyone since” Graeme explained that he thought his mum needed more support from the physio’s to keep her mobile and walking properly. “I haven’t asked for more, because I wouldn’t know who to ask! When you’re told something you just have to accept it – there doesn’t seem to be any caring at all.”

“I don’t feel like I can help her with things like that in case she falls over, then I’d have to call the ambulance and all that. I’ve had to do that before because if she falls I can’t pick her up on my

own. Sometimes they will just help me lift her up, other times they might take her to Barnstaple to check her over but then I would have to bring her home. We couldn't do that now though because she is too weak to get in and out of the car"

"I don't know what else would help us because I don't know what is available – I'm clueless really and that makes you feel more vulnerable. It would be nice if someone could come in every now and again to see how we were getting on, to do an assessment and reassure you that you are doing OK, and to let you know if there was anything that could be provided that might help make things easier rather than just struggling all the time. I am always struggling. We don't get any help from anywhere. It would cost the government £3,000-£4,000 per week if mother were to go into a home and I receive less than £100 in benefits. I've given up everything to look after my mum and I've had nothing back"

"It would be good to have something local in place that works and is reliable, and easy to get at (so you don't have to push this number and then wait with music etc). You need a number to call and a person to talk to who can help you."

"At this moment in time we don't need the beds but tomorrow we might, and we did before as well. It's just good to know that there is somewhere local that you can go to."

Patient Story consent form

PATIENT COPY

Name of person: ……

Or, if relevant, name of parent/carer/guardian……

Statement: I am/represent a patient of Northern Devon Healthcare Trust and I agree that this is a true reflection of the experience I shared with Nellie Guttmann, Engagement Lead on……(date)

□ I agree for my name to be used when sharing my experience for the reasons given below

□ I would like my experience to be made anonymous when sharing my experience

Reason for Story: The Trust would like to increase understanding of the type of care that can be delivered in people's homes. We will also use patient stories to inform future service developments

Trust contact details (this is so you can call us if you change your mind: 01271 313 971

Signed……

Date…….

TRUST COPY

Name of person: …….

Or, if relevant, name of parent/carer/guardian……..

Statement: I am/represent a patient of Northern Devon Healthcare Trust and I agree that this is a true reflection of the experience I shared with Nellie Guttmann, Engagement Lead on……. (date)

□ I agree for my name to be used when sharing my experience for the reasons given below

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Trust contact details (this is so you can call us if you change your mind: 01271 313 971

Signed…….

Date…….

Patient Story validation form

Independent Validation of Patient Story

I *(name of person)* ……., as a representative of Healthwatch, have listened to the recording of (*name of patient*) ……'s patient story carried out on (*date*)…….. By Nellie Guttmann, Engagement and Involvement Lead for the Northern Devon Healthcare

NHS Trust

Validation Statement: I agree that the write up of this story is a true reflection of the experience the patient shared with Nellie Guttmann on the above date.

Confidentiality Statement: Where indicated, I agree to maintain the confidentially of patients and I will ensure any references made to these stories will remain anonymous and comply with the Data Protection Act (1998)

Comments:

Healthwatch representative
Print Name: ……..

Signed:……

Northern Devon Healthcare NHS Trust representative
Print Name:……

Signed:……

Date……