



Doncaster
Clinical Commissioning Group

Doncaster Discharge Project

A research based resource to put patient voice at the heart of the commissioning process



Contents:

- Page 3 About the project
- Page 4 Why might patient voice, derived from research, be useful in the commissioning process?
- Page 5-8 Pen Portraits
- Page 9 Where can patient voice, derived from research, be used in the commissioning process?
- Page 10 Key implications from this research for commissioning
- Page 11 Links, information

The Doncaster Hospital Discharge Study

Why was the project undertaken?

The Doncaster Hospital Discharge study was one of the key studies undertaken as part of evaluation work on the Better Care Fund, jointly commissioned by Doncaster CCG and DMBC and undertaken through the Doncaster Academic Partnership.

DMBC were interested in finding out about people's experience of hospital discharge. So the study followed people from discharge and tracked how they coped, their experiences of services, as well as the impacts and outcomes for them and their carers alike. The study was not about evaluating the services – it aimed to provide a unique insight into what it feels like to navigate the health and social care system.

Research methods

The study involved in depth semi structured face to face interviews with people recently discharged from hospital (and their carers) within a couple of weeks of hospital discharge and referral, and then at around 91 days and at 6 months. Regular telephone contacts between interviews and for a period of up to 12 months were maintained to obtain updates in relation to their care and outcomes.

“ We know how many people are discharged... but we don't know how they are doing ”

(senior commissioner)

Turning insight into action – using the research findings

Pen portraits - research based narratives

The narratives were developed using the research findings from the Doncaster Hospital Discharge study. These research informed narratives are based on participants in the study but also draw on common themes and key issues that came out of the co-production sessions (see below) as well as those from the research analysis itself. Unfortunately, due to the nature of the data and the low numbers of men in the study, there is a gender bias in the narratives.

Co-production - working with health and social care

We ran two workshops, the first exploring the data generated by the research and the second understanding where in the commissioning pathway patient voice might best be used to inform commissioning practice. We also wanted to understand the best form for the research to be presented that would be useful to commissioners.

Why might patient voice, derived from research, be useful in the commissioning process?

Some quotes from health and social care colleagues

“They help demonstrate the importance of all services within the system working together. When we’re commissioning something we can briefly list the interdependencies (services and organisations that they will have to partner with) in the spec and can ask a question about how the service provider will work with partners etc. but we don’t necessarily think of it as a system sitting around each family that will probably change over the course of a contract as contracts change and organisations change. The narratives could highlight this.”

“They may help with problem solving or planning for potential problems during the contract management stage. If a specific problem arises the narratives may help shed light on why this is. For example, the service being delivered may be getting propped by unregistered carer like Jane’s daughter but inevitably that might change but may get missed unless reassessment is done. It may also help commissioners and service providers think about the whole family, rather than just the person.”

“For me the pen portraits are real stories about real lives and we as commissioners should be using them as real examples of where people fall through the gaps and where some of our key big ticket items such as social isolation and loneliness/inequalities could be addressed. Reflecting on my recent tender process with tier 3, I agree it would have been much better to have some real case studies rather than the ones we create in normal practice.”

“These provide an evidence based case study to use as part of the tender process. I think these are far better than the case studies commissioners develop and reflect the real complexities of people’s lives. I think you’re right that what shouldn’t be done is ask tender questions like “How would your service deal with Kate’s case” It should be more like “How would your service provide the right care and support to meet the needs of people like Kate, taking into account the wider systems and partnerships that it will sit within.”



Audrey's Story

A narrative based on research findings to help put patient voice at the heart of decision making.

Audrey loved getting out of the house and meeting her friends. She was a regular church goer and liked to visit the local shops and parks. She also spent time at the leisure centre where she would swim a little.

Unfortunately, Audrey began to have a few falls at home but didn't like to tell anyone as she wasn't one to make a fuss and always put on a brave face. However, one fall was very bad. She broke some bones and ended up in hospital for over a week. *"It's been horrendous really, I would have been better if I'd been more open with it but I've kept it to myself and thought that people would think I was moaning all the time."*

After leaving hospital Audrey spent 6 weeks at Positive Step while she got better. She really enjoyed the company and having people around to talk to. She also enjoyed meal times too and realised she was eating a lot better whilst she was there. Although she wanted to be back in her own home, she began to worry about what it might be like and didn't know how she would cope or who would help her. *"I shall miss the company and sitting down with people for meals, I don't like eating alone but I know I've got it to come, but it'll still be great, you know what they say, there's no place like home."*

When Audrey did go home, care staff visited so she could get showered and this helped a lot. She also paid for someone to help with cleaning and laundry as she couldn't really manage this herself anymore. Audrey had been quite an active lady and she really wanted to get out of the house again. The problem was she couldn't walk very well and was frightened of falling again so she needed to use a wheelchair. She couldn't manage the wheelchair on her own but didn't like having to ask anyone to help. She began to feel very isolated, lonely and useless. Her mood became very low. *"I was very active and I went swimming and all things like that, I can do nothing now, I'm absolutely in other words useless, I feel useless cos I can't stand for long hardly, well you could say I can't stand, I just rely on the chair all the time."*

It wasn't until a lady from the University came to do some research that anyone realised how lonely and isolated Audrey had become. After talking about how she felt she said the researcher could contact Age UK for some help. They arranged for a befriender to visit Audrey. *"I look forward to seeing her (Age UK befriender) and I'm very pleased to see her."*

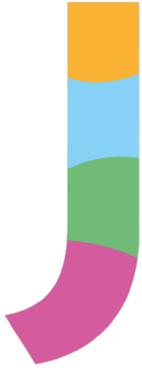
This was great, but Audrey really needed to get out of the house so in the end she paid for someone to help her do this. She is now getting out a bit and is feeling much, much better. She really looks forward to her Wednesday trips out. *"I love Wednesday afternoons, I love fresh air, I love to get out."*

What Audrey's story tells us...

Although Audrey did get some care and practical help to be at home her needs as a person were completely missed by anyone in the health and social care system. This had a bad impact on her health and wellbeing.

Audrey didn't know who could help her to get out of the house and do the things she used to like doing so she could feel like herself again.

Fortunately, for Audrey she was able to pay for someone to take her out, otherwise her situation would have probably got worse.



Jane's Story

A narrative based on research findings to help put patient voice at the heart of decision making.

Jane lived alone in a remote village on the outskirts of town. Even though she got lonely, she loved her home and wanted to keep living there. *"I just want to be able to keep active, go into town, keep my marbles"... "I'd like to be at home to sleep."*

Jane needed some help, so she paid for some care and daily tasks like cleaning, washing up and shopping to be done. This helped a lot. Jane's daughter lived quite close by and did as much as she could to help her mum, but she was struggling herself as she had breast cancer.

Jane's health got worse and she had some problems which meant she needed more care. She sometimes needed to go into hospital for a couple of weeks at a time and every time this happened her care was cancelled so she couldn't get back home. It was hard for the Council to find any care companies who would visit Jane as she lived so far out of town. It took a long time to sort care out again and she was left waiting in hospital. Jane was frightened as she didn't know what would happen to her or what help she might get.

When Jane did get back home the care wasn't enough to meet her needs and Jane and her daughter were left struggling to cope. They didn't blame the care staff as they were told by their bosses what they could and couldn't do, but the lack of flexibility didn't make sense to Jane and her daughter. *"I try and get down every day but if I don't get down them pots, the food's drying on them... but they're saying 'we don't wash up, I've got breast cancer and the carers were supposed to look after her, they were supposed to do her daily washing, her clothes, which they say they don't do'. 'If you go private... you can ask them to do things, just a bit of ironing or washing or on their way they can call at the shop, whereas these have got set things they can and can't do... so they can't use a grill, put anything in the oven.'"*

Jane developed breathing problems and was taken to A&E a number of times. Each time she was given oxygen there and got much better and was able to go home again. The doctors said she needed oxygen at home to stay well but Jane's daughter struggled over many months to get this sorted. Because Jane didn't have it, she went into hospital again... *"No she still hasn't got it now, this is why, this time she's gone in."*

Jane's daughter was really struggling as the doctors, district nurses and social workers did not seem joined up and she had to chase people all the time. This really started to take its toll on her and she didn't know who could help her or her mum. *"Yeah, I know I've got to carry on for my mum's sake, but it does get me down, I get so frustrated, I go every day and there's one thing or something else wrong and I have to ring somebody...I rang the district nurses when she came out last time, I said 'have you got my mum on your list for a follow up?' 'no' I rang my GP and they hadn't got anything to come out and assess her."*

What Jane's story tells us...

How home care is organised and delivered is inflexible. This meant it was hard to get someone to visit Jane and the care delivered didn't meet her needs. Jane's daughter was ill but was left to try and sort things out for her mum. Nothing seemed joined up and she struggled to find who to talk to and who could help. Jane's daughter didn't have anyone to help her or know about any services that could support her and the situation took its toll on her health and wellbeing too.

There were many missed opportunities to help them both. Even the oxygen Jane needed didn't get sorted out and this meant she ended up back in A&E.

Unfortunately, Jane passed away.



Kate's Story

A narrative based on research findings to help put patient voice at the heart of decision making.

Kate and her husband were married for nearly 60 years and had one son. They had a lovely home which they had lived in for most of their married lives. Kate's husband had Parkinson's Disease, but she managed to take care of him as well as doing all the house work and other household jobs.

Their son liked to see his mum and dad as much as he could, but he moved to the other side of the country 20 years ago after he got a good promotion at work. He had a very busy job and couldn't visit as much as he would have liked but they talked on the phone every few days. Unfortunately, when Kate got a bad infection in her wisdom tooth she had to go into hospital for some treatment. This was a very stressful time for her as she was really worried about who was going to look after her husband. Fortunately, her son managed to get some time off work and was able to come and help.

Kate's son was getting worried about his mum and how she was going to manage to keep looking after herself and his dad. When Kate came out of hospital her son found out about Home from Hospital and Age UK. They were able to sort out someone to help with shopping and laundry. They also gave Kate information about other services she could pay for if she needed more help. *"So yes it has helped me (Home from Hospital Service) but yesterday when the lady came I said to her 'I feel guilty you doing all this cos I thought I could do it' but it just takes that burden off you, so maybe I might try to have somebody come every so often, my son wants me to do that."*

Later that year Kate was told her husband had Dementia. His health began to get much worse and it got harder and harder for Kate to care for him. But Kate didn't see herself as a carer and thought it was her job to look after her husband. When her husband was diagnosed with Dementia nobody talked to them about any extra help they might be able to get so she just kept going.

Kate began to get very tired all the time. She started to struggle with all the jobs she had to do as well as look after her husband. She didn't realise how hard she was finding things. *"I just get tired, that's the thing. We've got Age UK, and other things we can ring too if we need help."*

She didn't like to make a fuss or worry her son. It wasn't until things got really bad that she started to think about asking for more help. *"I'm coping but I'm going to see if I can probably have someone give me a hand at times. I do feel tired, when you have to cope with just about everything, the finances, answering the telephone, post, you know everything."*

Unfortunately, before Kate managed to arrange for more help, her husband had a few bad falls and had to go into a care home. Kate and her husband had always said that, when the time came, they wanted to die in their own home, but Kate's husband ends up dying in hospital.

What Kate's story tells us...

Some people don't realise they are carers and don't always ask for help.

Opportunities to help Kate and her husband were missed when he was diagnosed with Dementia. Help at this point may have meant things could have turned out a lot better for both of them and Kate's husband might not have needed to go into a care home.

He may also have been able to die at home.



heila's Story

A narrative based on research findings to help put patient voice at the heart of decision making.

Even when she started to find it hard to get around Sheila didn't think she was doing too bad really. Her son helped her as much as he could, but he works full time and is a single dad. *"He's good, he's hoovered through...he's cleaned my fridge out, re-stocked it with what I need. I'll not go hungry, I've got a cupboard full of tinned stuff, he's really good like that."*

When Sheila began to fall out of bed a lot her son arranged for her to have a pendant alarm, but she didn't always like to use it and once laid on the floor all night until she called for help. A couple of times she had to go into hospital then Positive Step until she got better. Sheila needed some help to cope at home so the Council arranged for some care staff to visit however, they only visit twice a day for 15 minutes which isn't enough time to do everything. *"But they've only got quarter of an hour to do it in, that is ridiculous."*

Some days Sheila struggles to get up in the morning and it takes her time to get moving. So a couple of times the carer has come back after their shift has ended to help her get showered. *"There's many a time they want to come at 8 o'clock in the morning [to give Sheila a shower] and I say 'I can't do that cos I can't get myself together' and being young they don't understand that as you get older you get slower, you haven't got the energy to move about'. 'I asked her [the carer] this morning 'have you got time to give me a shower' 'well not just now but I'll come back ...and she did bless her."*

Other people visit the house too but Sheila is often confused about who they are and why they are visiting. She has no idea what is going on and strangers just walk into the house. Things just don't feel joined up. *"Cos people walk in and they don't tell me, it's not nice."*

Sheila wanted to be able to get out to the shops and bingo so she bought a scooter, but it is getting harder now to go out on her own. She was dreading winter coming when she thinks she won't be able to get out. *"It's just when the dark nights come...Winter, dark weather, nowhere to go, looking at black space ...but it means I can't get out and there's nowhere to go anyway, there's only Asda and I can't go just riding round streets."*

Sheila has started visiting a Day Centre now which she really enjoys as it gets her out of the house and stops her feeling quite so lonely. She is feeling much better about the future. *"I think this winter's going to be different, just because I'm going out and meeting these new people, some of them less fortunate than me...and they take us out for dinner...and there'll be a Christmas party."*

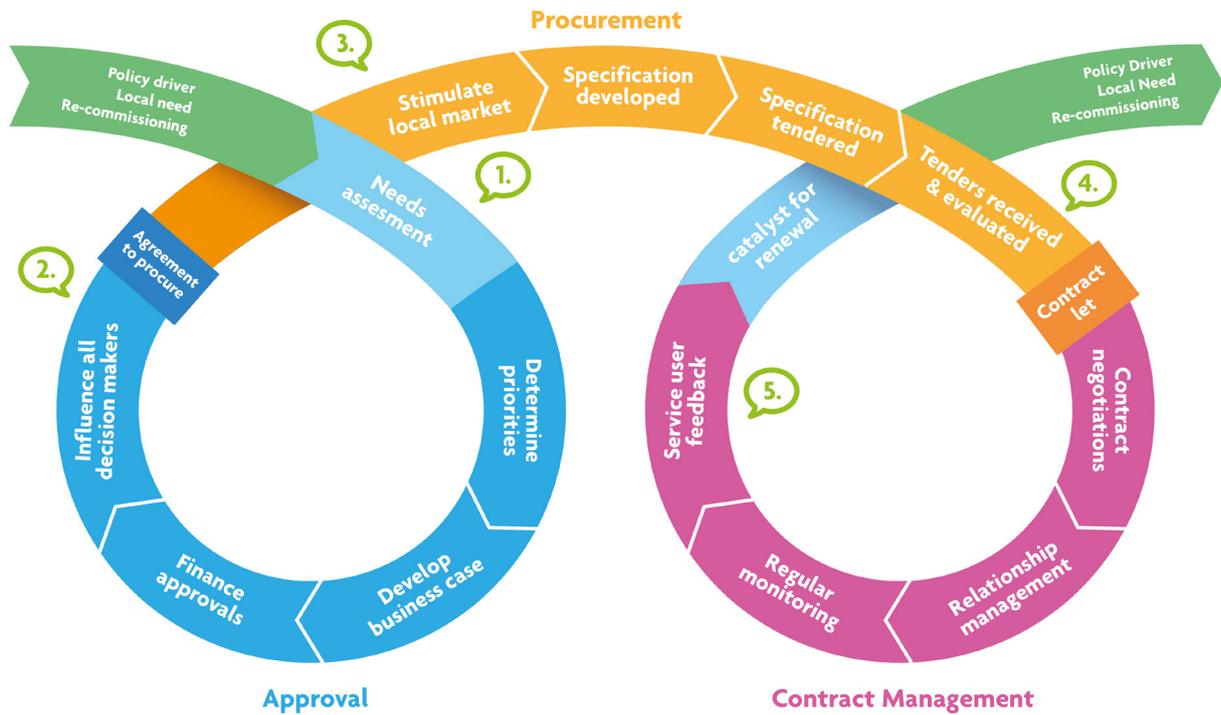
What Sheila's story tells us...

Sheila needed help to keep her independence, but the carers don't always have enough time to give her the care she needs. The carers are filling gaps in their own time and without them going above and beyond, Sheila might be left struggling.

Although Sheila has care she often feels that she doesn't know what is going on and it isn't joined up. She thinks people don't talk to each other and they don't talk to her about it either.

Getting out of the house to the Day Centre has made huge difference to Sheila's life. She is looking forward to the future in a more positive way.

Where can patient voice, derived from research, be used in the commissioning process?



- 1. During needs assessment**

These narratives can be used to supplement needs assessment processes to help illustrate the needs of service users and their experience.
- 2. To help support the case to decision makers**

Our narratives can be used to help persuade key decision makers to act by providing research inspired stories which explain how it feels and why a need should be addressed.
- 3. Stimulating the local market**

Our narratives can be shared with prospective providers to convey issues that their application might need to answer; it can help set the tone of ensuring people are at the centre of the service.
- 4. To evaluate received tenders**

Providers can be encouraged to consider how they might tackle the key issues identified within the narrative and this can form part of the evaluative questions.
- 5. As part of service user feedback**

Referring to these narratives in conjunction with other feedback can be used to understand whether the service is meeting a need. The narrative acts as a helpful reminder of what it can feel like to be within a service.

Key implications from this research for commissioning:

- Services should be flexible and take into account the wider systems that they sit within
- Services may need to have discretion and reactivity built into them so that they can deliver flexibly, for example, increasing care quickly in the short term to meet a short term need.
- Performance targets need to be more creative so that service providers aren't disadvantaged because they have worked creatively to meet the real needs of a person.
- Service pathways should show all the interdependencies, including wider organisations and systems.
- The contract management process should take into account changes in the wider system and flex to meet these changes.

“We do list what services and organisations the service will work with in the spec, but that is used more to remind the service provider who they should be working with (or to force them to work together!). Using the narratives helps to get you thinking about how the interdependencies within the system really work and how they impact on the person.”

Links and Information

Interim report:

<https://www4.shu.ac.uk/research/cresr/sites/shu.ac.uk/files/doncaster-hospital-discharge-pathway-interim-findings.pdf>

Final report containing case studies and timelines:

<https://www4.shu.ac.uk/research/cresr/sites/shu.ac.uk/files/doncaster-hospital-discharge-pathway-study-final.pdf>

Acknowledgements

Our thanks go to DMBC staff who have supported the project and who contributed to the co-production workshops, DMBC, Doncaster CCG and Healthwatch Doncaster for supporting further development of the discharge study findings and helping translate findings into action, the Centre for Regional, Economic and Social Research at Sheffield Hallam University and The University of Sheffield for their involvement in the initial research as part of the Doncaster Academic Partnership. Our final thanks go to the all the participants, their families and carers who took part in the original hospital discharge study, without their continued commitment to the project none of this would have been possible.

This project was supported by the NIHR CLAHRC Yorkshire and Humber. www.clahrc-yh.nihr.ac.uk.

The views expressed are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.



Sheffield Hallam University

Doncaster Discharge Project : a research based resource to put patient voice at the heart of the commissioning process

GILBERTSON, Janet <<http://orcid.org/0000-0003-3338-7590>>, HAMPSHAW, Susan, STOCKS, Amanda and WOLSTENHOLME, Dan

Available from the Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/25778/>

Copyright and re-use policy

Please visit <http://shura.shu.ac.uk/25778/> and <http://shura.shu.ac.uk/information.html> for further details about copyright and re-use permissions.