

Multi-Morbidity Patient Stories

Patient engagement was undertaken on the 14th and 18th November 2019 in preparation to present findings at the Local Health Economy Event on 27th November.

Engagement/involvement

On 14th November a commissioning support officer (CSO) attended the Cardiology Outpatients Waiting Area at South Tyneside Hospital to talk to patients.

On 18th November the CSO attended the Diabetes Clinic at Palmers Community Hospital to talk to patients waiting for their appointments. The CSO then attended the Renal Department at Sunderland Royal Hospital to talk to patients on dialysis who have multiple health conditions.

Target audience and numbers involved

The target audience was people who suffered from multiple long term conditions. The CSO gathered stories from 14 people but talked to around 26; some people were not relevant to the study or did not wish to participate.

Discussion with and feedback from the audience

The CSO discussed a wide range of issues with the patients through informal conversations so that they led the discussion themselves.

Issues discussed included:

- What it is like to manage multiple medications?
- What is it like going to hospital?
- What is it like going to your GP?
- How involved do you feel in your care?
- What is it like to live with multiple conditions in South Tyneside/Sunderland?

The conversations were very informal and felt more like a 'chat' about how they manage their multiple conditions and how they feel about everything associated with that. Key quotes, themes and stories were recorded.

The quotes that recorded and then used for the event were:

Patient 1

“When I first started coming to hospital frequently for appointments I started to get panic attacks. It was actually the other patients that helped calm me down and feel safe and comfortable to enable me to keep coming to the hospital.”

“Although it makes me feel a bit down coming to hospital all the time, it feels like my second home now.”

“I am on dialysis and I was offered to do this at home myself but I just don’t feel confident that I would do it right.”

Patient 2

“I also suffer from depression and anxiety but health professionals generally don’t ask about that when I see them.”

“You learn to adapt your life around your treatment/appointments.”

“I went to a tester session for rehab but I’m still waiting to fully start the programme. I could do some stuff myself but I don’t know what to do.”

“I feel like I have the same sort of appointments and the same sorts of conversations constantly. I honestly don’t see the point in some of the appointments I go to.”

Patient 3

“I take 19 different medications a day so I find it hard to keep up with what I take and when.”

“Sometimes professionals use words I don’t understand; especially in letters.”

“I struggle to get a GP appointment. If I do get one it is often over the telephone which I don’t like as much as speaking in person.”

Patient 4

“My legs swelled and no one bothered to find out the root cause until a GP reviewed my medications and made some changes which caused the swelling to go down.”

“I love my GP – she really takes the time to explain everything to me and answer any questions I may have.”

“Travelling to the hospital can be a nuisance. I usually have to arrive an hour before an appointment to make sure I can get a disabled bay.”

“I would like to be more active but having broken my back previously I’m not sure I would be capable.”

Patient 5

“If I ask about my GP about my meds they seem just as confused as me – it’s a guessing game!”

Patient 6

“When I get a letter to attend an appointment I often don’t know what it’s about; I just turn up!”

“The ambulance service is vital for me to get here but sometimes you can be waiting an hour or more to get one which takes a large chunk of your day.”

Patient 7

“I only found out about some things written in my notes when another doctor brought it up to me.”

Patient 8

“I’m at hospital three times this week. Once you start coming you feel like you can’t get away from the place.”

Patient 9

“Sometimes you have to co-ordinate your appointments around other appointments. It’s a nightmare!”

“If I go to my GP I feel like there is a lack of knowledge about all of my different conditions/medications and how they interact.”

Patient 10

“...as I’m here a lot it makes a real difference that the staff are so lovely.”

“I’m signed up to the service where I can view my blood test results online. It’s about taking back some control over my own body.”

How the information and feedback has been utilised

The information was used to develop a presentation for the Local Health Economy workshop. Quotes from the patients were used to highlight key issues linked to the broad themes discussed with them; this allowed the audience to consider the realities of living with multiple chronic conditions in South Tyneside and Sunderland.

The quotations were then integral to the facilitation of a workshop on tables with a mix of clinicians, commissioners, social workers and public health representatives. The workshop centred around developing a problem statement that reflects the current issue – how we care for our LHE population who have multiple chronic conditions.

This workshop was used as the starting point for a project surrounding how we can change the management of patients with multi-morbidities to work better for both the system and for patients.