

21 July 2020: Cancer Services Partnership - Online Focus Group

Facilitator	John Boyman - Head of Public Relations – Strategic Projects Ellie Stennett - Marketing Officer	Engagement Team	SE
Independent Chair	Frankie Webb		
Registered participants	19	Participants on Zoom	11
<p>Questions/Comment raised pre-event at registration / website [comments box on Eventbrite registration form]:</p> <p>You need to consider how the hospital can be accessed and have excellent public transport access; alongside sufficient parking for both staff, patients and visitors to in patients? Separate initial parking for anyone taking a patient to A&E as an emergency? Tied up thinking regarding what services are best placed where?</p>			
<p>Questions/Comments raised during online event:</p> <p>QUESTION POSED BY FACILITATOR: Change to health services over time - experiences on how health care have changed over the last 10 years.</p> <p>COMMENT FROM CHAIR: Cancer services are for the patients but also their families and carers and we support them all. So let us know whether you are talking as a patient or as a family member.</p> <p>COMMENT: I've been living with cancer for 30 years so I've seen a huge number of changes. I initially had my chemo with the doctor giving me the chemo, but it's far better with the cancer nurses who are fully trained. Many more people can be treated and it's a much more fluid system. The addition of the cancer specialist nurses who can help you and let you know about all the other things that are going on in that area. One of the biggest things when suffering from cancer is the consistency of staff. More value needs to be placed on how important that is to the patient.</p> <p>To have new people all the time who are asking you the same basic questions again and again and again, is wearing. When you build up a relationship with a nurse. They have got such knowledge that they should be treated as a different category of nurse as they build relationships with people. People may not survive and they need to be helped through those traumas as well. It's a hard job to do.</p> <p>Lots of people nowadays can have ports and lines in where they get their treatments. I had 15 years worth of infusion through the veins in one hand. And therefore the cannulation of that is key because you only get one set of veins. Those sorts of things are critical. Not everyone wants or needs a port because it restricts other areas of your life.</p>			

You as a patient need to own your own body but the people looking after you need to be aware that although there are prognoses, it is possible to survive this and you need to plan that journey for someone to carry on living alongside it. When things are understood, you need to make sure you need to remember those who are on long treatments otherwise we fall off the wayside.

COMMENT: I was diagnosed with breast cancer 10 years ago. The key point - when I was getting the results of my operation and tests, it was a time when the consultant I'd developed a relationship with and my CNS were both on holiday at the same time. When it got to the point when I was told the bad news there was no one there for me that I knew. There wasn't a CNS. It had a big impact on me.

COMMENT: I'm coming from a slightly different angle - I was in isolation for 16 months in Wessex ward but I was also a nurse. As a nurse, I know that the one thing that is paramount is to look after the family as well as the patient. I experienced something whereby my family wasn't looked after on any level and I would hope that in a hospital there was provision not only for the nearest and dearest but particularly the children of that person. eg. something available for a parent going for chemo, or for me for an extended period of time. There was nowhere for my kids to go and do their homework, no one for them to talk to, they were left with a lot of unanswered anxiety. It needs to change. I know we're getting rooms for counselling for patients themselves but I see a huge void for care for the carers. If your family feels cared for, you feel cared for.

COMMENT: We lost our daughter to cancer and as her main carer, I know the carers don't get the attention they really need. My daughter had a small child who wanted to come and spend time with his mum. Salisbury hospital did have a play counselor in the hospice - she would talk to them through play. The fears you'd expect a little one to have weren't there because he was referring to what this lady told him, We need to adopt this. I know we're short of chemo nurses and they take a long time to train. We need more trained chemo nurses - they have the knowledge. They're struggling to get people from the bank when someone goes off sick. My daughter was always desperate to see the same person. It's important for us to know that our special ones are being cared for.

COMMENT: My care at Basingstoke, although not as technically, clinically advanced, was far superior to Southampton. I can honestly say that the dedication of those staff on Wessex ward was incredible. For a long time, Basing and Wessex unit lacked direction. The matron didn't appear to be quite on it and sadly recently they lost the most incredible matron. When you have a leader at the helm, it attracts a lot of staff wanting to come and join that expertise. The clinical excellence at Southampton was incredible but they lacked the care and passion and old-fashioned nursing skills that I was lucky enough to have at Wessex. It's a balance - you want to feel well-cared for but the quality of life while you try to exist is made wholly more bearable when you experience staff like I experienced in the Basing unit. I know they have changed the practice since I was there, and I believe it has got even better. As regards consistency of care, they have petitioned for 2 lots of staff up. So there was always the same set of staff looking after the Basing patients and the same set of staff looking after the Wessex patients. That was a very good piece of division. From Southampton - as soon as something gets big, you don't get the same level of ownership from a member of staff, you don't get the same level of pride, from the cleaner

to the consultant. If this new hospital was enormous you might lose that edge that I feel we have at Basingstoke as opposed to Southampton.

QUESTION FROM THE FACILITATOR: The buildings - what are your thoughts on the condition of the buildings? How have your experiences been shaped by the conditions of these buildings? Have the conditions of these buildings ever had an impact on your care?

COMMENT: I have had experience of Basingstoke and I've had a lot done at Southampton. I've recently had some things at Winchester. The big issue with Winchester is the stress of parking your car. It's not possible to do park-and-ride if you have limited walking. I don't have a disabled permit. That means I need to park as near as I can to where I need to access. Yesterday I had an appointment at Winchester and didn't know where to go as I've never been there. With Covid going on there is a one way system in a hospital where it's so spread out, for someone with no sense of direction it is impossible to get back to where your car is parked. I understand you are stuck with the building as it has been designed but it's really important to consider accessibility and how people are going to get about. Maybe we need to consider having different entrances - heart problems in one entrance, or maternity in another. Or have one central reception where everyone starts.

I also had an incident - I worked in Winchester, and left 45 mins to get 5 minutes up the road from where I worked. I couldn't park and eventually I ran in 2 minutes late according to their clock and was very stressed, and they said no I had missed the time of the appointment I couldn't have it. I had a meltdown because I'd done everything I could possibly do. I needed to have the test so I could move further on with what was happening with me. Eventually they gave me the appointment.

I think the building and how it's designed and how it works need to have an awful lot of thought.

COMMENT: It's really important to look at the environment. At Basingstoke, they have made the best of a bad situation. It's a challenging environment. It's decaying. Being stuck up on the top as though it is embarrassing to have a cancer unit, it felt dangerous, traumatic to get up there. I think when they think about the cancer hospital or department in the new hospital, it needs to be on the ground floor with direct access so you don't have to move through the challenged environment of a general acute hospital like Basingstoke. The environment was welcoming, and the staff continuity was quite good and for the actual environment it was clean but it needs to be away from other departments.

COMMENT: At Wessex there were times all I wanted to do was to go outside and go for a walk when I was able to, but the thought of going down through the hospital and in the lift was terrifying. I refused to touch the door or anything - even now I am so paranoid. When I went to the BMI, having everything on one floor had a huge impact.

COMMENT: Priority needs to be direct entry from the outside for the cancer unit, and then to have green outside. Individual rooms. This is the way forward. The difference it makes to patients is huge and the difference it makes to families is even bigger to know that their loved ones are safe.

COMMENT: Being on the ground floor and being able to get to the outside is important. My daughter was in Salisbury and had French windows so she was able to open the doors

and go into her own area where she could sit when she was well enough. Fresh air is so important.

COMMENT: I had all my treatment at Southampton. I've taken friends to Winchester for chemo and scans. It's looking at other hospitals that do work. If everything was on one floor at Southampton, it would be a huge area to walk to. They have all the cancer units on top of one another, so you only have to go up and down in that part of the hospital.

Winchester - people waiting for drugs to come from Basingstoke - I was shocked because surely shouldn't Winchester have their own pharmacy. They had to wait and even ended up going home and coming back 3 hours later when the drugs had arrived. Maybe it was a blip but that really can't happen in a new hospital. It's stressful and they're hanging around all day waiting.

At Southampton - the Macmillan acute oncology service has an emergency telephone service. If needed they get an ambulance and get you in.

It is sponsored by Macmillan but in a new hospital maybe something similar could be put in place.

For my first chemo I was put into a ward. The lady next to me had been diagnosed a month before, and another lady was talking about how she had a 25% chance of being alive in a couple of years. That really scarred me for life. I wasn't ready for that, I'd only been told myself. To be put on a ward with people who are at the other end of treatment was tough. Maybe a thought about who is in which ward.

COMMENT: Something that works at Poole is a one-stop shop. Whereas at Bournemouth I went into one area for my mammogram, walked miles for an ultrasound, then walked back for my bloods then waited, then came back for another appointment. But at Poole it was done all in one area. A one-stop shop is best so you're not walking around and around as it is really distressing. It's stressful enough but then to have to walk around a hospital is hard. In one place, having all the clinics and all the information is important.

COMMENT: Parking at Winchester - I rang the clinic and said I was stuck in the queue for the car park and that was fine. But it must be incredibly inefficient for the clinics when people can't get there because of the parking.

I had 4 or 5 different visits to the hospital for diagnosis. It took forever, fortunately it turned out to be alright. Had it not been alright, the delay would not have been a good idea.

COMMENT: If you're an inpatient for a long time Two things you really need in your room -
1) a fridge. Several of the consultants are worried about the infection risk but at Southampton they have them and from a dietetic point of view it's really important
2) enough place to put your stuff because there isn't enough in that tiny little thing.

QUESTION FROM CHAIR: Can we learn anything from using the BMI hospitals at the moment?

COMMENT: BMI in Sarum Road, one thing that is obvious with the pandemic is that you need to screen patients before they go in. It's especially important for people with cancer. So one thing that needs to be considered, is if there is a separate entrance there should be an outside space which they could adapt or put up a gazebo should the need arise in the case of a pandemic.

COMMENT: When the Basing unit was in Basingstoke, I volunteered there. When there was rumour of a new hospital I asked the patients what they thought was important. These are what came up all the time when talking to patients and their families: 1) a cafe area

near a waiting room for when they have to wait for a long time, and the partners could have another space to go to. 2) they wanted some kind of music playing in the background to take away a lot of the sounds going on and 3) to be near an open space where if they had to wait half an hour they could have a walk or sit, especially if it was a sensory garden.

COMMENT: I feel concerned that there's an illusion that because the BMI place is private it's somehow better. It purely feels better because it is a single building and direct entry with lots of individual rooms. Without doubt BMI at Winchester is a shabby building. But the environment on one level, ground floor with individual rooms is good.

Having individual rooms to break bad news. The psychological impact of someone else in that room is profound.

COMMENT: I had an experience when I was on Wessex when I was in a room with another lady who was terminal. The doctor came in to talk to her, her husband and their two teenage daughters and they said there was nothing more they could do for her when I was in the room. I felt like I was intruding - they could have moved me somewhere else. The nurses were mortified when they realised. The impact that had on me was horrendous.

COMMENT: The BMI has a perfect structure but let's not get swept away that it's perfect.

COMMENT FROM CHAIR: Don't forget that we've spent a long time designing what was going to be the cancer treatment centre which will be used and not wasted. One thing that did come up and found to be favourable was that patients had pagers so patients could go to a cafe and be paged when they needed to go back which would get rid of a lot of the stress of just sitting in a waiting room.

QUESTION POSED BY FACILITATOR: The opportunities are exciting but there are a lot of difficult decisions to be made, for example centralising services such as maternity and emergency departments. Some people may have to travel further to access specialised care.

COMMENT: Without doubt if you're going to get excellence and continuity, personally I'd travel miles.

COMMENT FROM CHAIR: Everything that we're talking about is for a section of the population across the board - people who can get there by car and who can travel. We've got a wide demographic - disabilities, very elderly and we have to think of them when we plan things. If we're saying we're centralising certain things and have a centre of excellence, we need to make sure that everyone can get there. We need to design for the whole population.

QUESTION POSED BY THE FACILITATOR: How far would you like to travel? Is there a limit?

COMMENT: You have to think about not just travelling time but also parking time. If you drive 40 minutes but can then park and get into the hospital that's one thing, but if you have to drive 15 mins but wait 40 minutes to get into the car park, then that's another. If it's a purpose-built building the changes of public transport being useful are quite remote. As much as we'd all like to not be using our cars, I just can't see any other solution.

COMMENT: A lot would depend on how the patient is feeling on any one given day. If they're feeling rubbish that will have an adverse effect on how far they feel they want to travel. They may not even want to go outside their own front door. At times like that, the closer to home they are the better.
Not sure one fits all is going to happen.

COMMENT: I think you need to go back to the carers and family - if you're in hospital for a long time and it's a long way for your family to travel, that will have an impact on your family not just you.

COMMENT: When I was at Basingstoke I had someone from my family come every day, and my children were over 12 so they were allowed. When I was at Southampton they visited me once a week because it was a long way. My husband came more regularly but my daughter suffered enormously as a result of that. It does have very profound consequences when the family has to travel for a long time, particularly when the traffic is as bad as it is in Southampton.

COMMENT: I have been living with cancer for 30 years, and I also have a son with down syndrome. He was 5 when I had my first surgery. For my second surgery 6 years later, the consultant knew I would only be able to cope with him as all he wanted to do was hug me which wasn't possible with the surgery I was having. No one was queueing up to look after my son. In the end they were able to move the operation back to Basingstoke so we could cope better which made all the difference to me at the time.

COMMENT: This is more about what we can have nearer home. I can remember going to chemo, then a blood test, then the results and it goes on and on. If there was some way to have blood tests locally with instant results to the chemo unit it would save a lot of stress.

COMMENT: A friend has just finished her chemo - she has a nurse who comes to her house, does her blood, then phones an oncologist, then treatment starts.

QUESTION POSED BY FACILITATOR: Are there any particular services you'd like to see provided in certain areas within the hospital and/or community?

COMMENT: A friend of mine is having chemo privately through Spire and has it every week. A nurse comes on a Monday morning every week, does her bloods and takes them back. She has a phone call with the oncologist on the Tuesday ready for her chemo on the Friday. She says that works very well.

COMMENT: Homecare - there is the ability, so long as we have the experienced community staff, to do drop-ins for blood tests and sometimes administer some medication. It does work in some areas. It's invaluable, receiving inpatient care at home meant that we potentially saved being in hospital 4 times a week. Sometimes I had to drop my daughter off at the door of the hospital and she was so weak she couldn't walk very far, she'd just slowly have to walk along the walls. Allowing people to have tests at home is possible, it just needs thinking differently.

COMMENT: It's about 25-30 minutes to Southampton hospital when I was having my treatment there, but they did offer chemo at a hospice 5 minutes from my home. They used to have a twice-a-week outpatient clinic there. That's something to think about - local doctor's practices, hospices or local areas that could be clinically clean and maybe a team of nurses in the community, would work a lot better.

COMMENT: We used to have a chemo bus but unfortunately the hospital couldn't keep funding it. But a mobile treatment centre was very well received especially in outlying districts where it was difficult for people to get into hospitals.

A friend is having chemo treatment in her house. When she's been so sick, it's been amazing that she hasn't had to get on public transport to get to a hospital. But on the downside it is a private service so she's paying. If this could be done on the NHS it could help many people.

QUESTION FROM THE FACILITATOR: If they were to centralise, what do you think should be taken into consideration, and what would you like to see if centralised?

Does anyone have any final thoughts and comments they'd like to make that you'd like to cover?

COMMENT FROM CHAIR: If we're going to have things centralised, then I'm assuming that's going to include radiotherapy and everything combined. We should be talking about everything in one building, rather than having to go to different places for different treatments.

COMMENT: IT - One of my biggest bugbears is that if you have treatments across different hospitals they cannot access anything which means you have to have tests done again. I have an experience during Covid and the doctor had no access to my scans; it was potentially dangerous. There needs to be joined-up thinking so that wherever you are your information needs to be available - it is a national health service, information needs to be available nationally.

COMMENTS: The government did try 3 years ago to get all systems to talk to one another and they ploughed millions into it and had to give up. I saw that in Taiwan they have a little card which the consultant pops in a machine which contains all their information. So when the patient goes to see another doctor they have all the information on this card. However, there is no back-up in hospitals so if you lose your card the information gets lost. It was interesting that you just carried a card and it's accepted anywhere in the country.

Chat download anonymised

thank you XX for sharing your experience

you're an inspiration to us all!! Thank you for sharing.

Totally agree XX. Thank you for sharing

Thank you XX for sharing.

Very good points.

Basing unit and wessex ward do have a 24 hr line invaluable service we have used this and still can. Never feel alone

Totally agree XX. Some patients brought their own in!!

Good idea = the use of local clinics/hospices for delivering chemo locally and eg. PICC line flushing - eg. Mountbatten at West End had an outpatient clinic 2 times per week from Southampton Hosp and also in Oakhaven Hospice.

eg. Rads dept waiting room in Southampton hosp has a tucshop with drinks and snacks as often long waits with rads.

a comment from a support group member - having chemo in isolation in private hospital is great from infection point of view, but she misses the chat and contact and reassurance and advice from other patients having chemo together.

thank you very much everyone for your contributions. Unfortunately I am having to go.

I need to leave now, sorry, but it has been a good discussion. All the points that I had from our clients have already been mentioned by others. Good to have the chance to contribute. Best wishes everyone from XX.

30-45 mins [travel time]

There is always the option of hubs for treatment

Sorry I need to go as I have another meeting. Some great inputs.

Homecare..

a friend having weekly chemo at The Spire in Southampton has weekly nurse come to house to do bloods - she said its very good as she doesn't have to travel 30 mins to hosp for a 5 minute blood test..

Sorry, I have to go. One thing I wanted to say - why do we have to see the consultant before having scans/tests etc? They can't diagnose without the test results. so save their time until results.

Thank you everyone.

Thank you everyone, I have to leave now

Thanks for coming

Report written by: SE