

## **18 July 2020: Cancer services - Online engagement session**

<b>Facilitator</b>	Caroline Latta Charlton	<b>Engagement Team</b>	Gail Cobb Sian Elmslie
<b>Speakers</b>	Alex Whitfield – Chief Executive, Hampshire Hospitals NHS Foundation Trust Dr Lara Alloway – Chief Medical Officer, Hampshire Hospitals NHS Foundation Trust Philippa Aslet - Lead Cancer Nurse, Hampshire Hospitals NHS Foundation Trust Dr Luke Nolan - Consultant Medical Oncologist, Hampshire Hospitals NHS Foundation Trust Dr Charlotte Hutchings – GP and Deputy Clinical Chair for North Hampshire, Hampshire and Isle of Wight Partnership of CCGs Edit Galambos - Clinical Matron, Hampshire Hospitals NHS Foundation Trust Rachel Adam - Operational Service Manager, Cancer Services, Hampshire Hospitals NHS Foundation Trust		
<b>Registered participants</b>	61	<b>Participants on Zoom</b>	36

### **Questions/Comment raised pre-event at registration / website [comments box on Eventbrite registration form]:**

To ensure that we have a centre located where people can get to readily and have many supportive services alongside treatment

Empowering people with cancer is essential and combating misinformation is crucial to achieve this. Support from registered health care professionals to protect the public's health is vitally important and HHFT's development is central to ensuring this occurs. People are very interested in how food can affect health and the HHFT cancer team need to ensure registered dietitians are utilised across the trust for this end.

Location very important to staff. Public transport links and parking. Ensuring staff who will actually be working there are involved in the design process of the treatment areas ensuring they are user friendly

It is essential that cancer patients/carers are included in this event. It should be advertised more widely

We need something like a maggies centre not just for the patients living with cancer but also for those supporting patients with it. It must include facilities for psychological support. Also the isolation beds in the hospital for those with blood cancers need addressing to be in isolation is a very traumatic experience and the facilities currently available are far from appropriate.

To review the support available to cancer patients post chemotherapy.

I do not want to lose small local hospitals. I feel they are not being used to the capacity they are able to and I worry that they are being run down in order to say that they should be closed.

I am very concerned that the excellent cancer services at the current basingstoke hospital may be lost or located further away. Travelling long distances for regular treatment over extended periods adds to the burden and prolongs recovery time.

provision of locally accesable hospitals

Health and social care providers need to work together with patients, families, carers and the public to build services that are developed to support the needs of the local population

I personally feel that I should be able to have any cancer treatments at Winchester, as I felt absolutely daunted and The added stress having to have radiotherapy every day at Southampton for three weeks. It would be beneficial for patients to have their whole package of treatments in one place, rather than having to travel to various hospitals. I had to travel to Basingstoke for my lymphoedema treatment. For my own well-being, I would have preferred having the continuity of treatment and after care locally and not having to travel places,, which caused anxiety.

discus with all branches of health and social care to form an integrated service accessible to all users

Basingstoke is an ideal place for a new hospital, with the M3 and B roads

Hospital should be sited where the best rail and road links are which in my opinion should be close to Basibgstoke due to excellent road and rail networks there should also be good car parking perhaps through building a multi storey car park which sufficient space for staff and patients, staff should NOT have to pay parking and those with Canver and other illnesses requiring long term treatment or long term hospital admission should not

The New Hospital must be close to Basingstoke if it is to provide continued good service to Basingstoke. It is the biggest centre of population in north Hampshire and is growing fast. Basingstoke Hospital is an amazing hospital. The staff go above and beyond and I have had excellent care. However I want to see cancer services improved in Basingstoke so that all cancer services can be accessed in Basingstoke. We deserve to have radiotherapy in Basingstoke for all cancers. A Cancer Centre as planned by The Ark Cancer Centre Charity must be an essential part of the new hospital. No one should have to travel from north Hampshire every week day for 4, 5 or 6 weeks or more to Southampton or Guildford for radiotherapy. Both are great hospitals, and my experience of Southampton General is fantastic BUT they are not local and the journey when you are not well is awful. The staff are what make Basingstoke hospital exceptional, the great trick will be to keep all that skill and transfer it to a new setting with excellent facilities and not lose any of what makes it great. Free parking would be a bonus for both patients and staff, the chances of better public transport is unlikely

when is the new hospital to be operational?

Basingstoke must have a hospital! My children were born there, and have been glued and plastered there after accidents. My husband has regular check ups there and I was

treated, and am still being supported, for Breast Cancer. The fact the hospital is local makes things so much easier.

#### **Questions/Comments raised during online event:**

**QUESTION:** How far behind in cancer services is HHFT at the moment? After Covid, a lot of things have spread out a little bit. Just how bad are we (waiting times)?

**ANSWER:** To reassure you sure we carried on with our time critical cancer treatments and surgical procedures as we were lucky to have access to the private sector hospitals. None of that surgery has been delayed. What has been delayed for a period of time was endoscopy, it was stopped nationally. We have now caught up with that. The other thing that stopped was the screening programmes (national thing as well). You can find some early cancers so that is a concern. What is a bigger concern is that people haven't been going to their GP to report symptoms. There is a lot of work going on to reassure people that we are open for business to get advice. Some people are still declining to come to the hospital for testing as they're worried. We're trying to reassure them that it is safe. There is a big concern there will be a potential knock-on effect.

**ANSWER:** We reacted very quickly to ensure we could continue the therapies so we combined units which has been very successful and continued all our patients' treatments seamlessly whilst following national guidance. I'm proud of the way as a team we were able to adapt and demonstrated to us how quickly you could change your services if you have to. We have learnt a lot about how to deliver systemic therapies and there are lots of changes we can make to make it easier for patients to have more tests done closer to home. We have universally adopted telephone conferencing and we're hoping to roll out video consultations very soon. I have learnt a lot about how medicine and how we practice medicine can be changed and for the better to make the experience better for the patients. We have learnt how we can streamline things, which is pertinent when we're thinking about developing new hospital facilities. We may not have been brave enough to make the change we have. We need to do as much as we can closer to people's homes but also make sure we have a state-of-the-art facility for those who do need to come for specialist or complicated treatments.

**QUESTION:** What I would have wanted as a nurse for a patient wasn't exactly what I needed as a patient myself. Having been in isolation for 16 months I do have some ideas for improvements. I'm hoping that patients in general can be used as a resource for the ongoing design because they are invaluable.

I would also really hope in the new facility that there was some sort of provision for patients' families, particularly for people with long-standing treatment as you only feel properly managed if your family members are looked after. The staff are phenomenal but there is no provision for where family could go.

**ANSWER:** Totally agree that we need to provide and their families. We don't have space for the families to go. We need it to work for everyone. It needs to work for both the patients and the staff - it needs to work clinically and care for the patient as a whole. We need to prioritise the psychological support and welfare of the patients as much as their physical treatment.

QUESTION: All the patients on another forum were keen to vocalise that the virtual phone clinics were fantastic but they all felt that they really wanted to see someone on screen face-to-face whereas the telephone wasn't sufficiently caring enough.

QUESTION FROM CHAT: Looking at your principles, what will your criteria be to decide what can be delivered at home, and how far it is reasonable for people to travel? What weighting will you give to clinical, economic, patient experience - and the cost to patients (so economic factors may involve clinician time and travel, but do they include the patient's cost?)

ANSWER: At this point we are at the input stage so it's really helpful to hear what matters to people. We're not going to be able to deliver everything that everyone wants where they want it. Some is limited by staff - so it is tricky to balance where staffing or big bits of capital mean you can't provide it everywhere especially something like cancer which requires a lot of appointments. You don't want to be travelling and getting on buses when you're poorly and potentially immunocompromised.

COMMENT: If you have to travel, then make it really easy for the patient when they get there. Before the radiotherapy unit opened in Basingstoke you had to go to Southampton and it was a nightmare for parking. If you have to have somewhere where people have to travel to because it makes economic sense, think of the patient having guaranteed parking for them and don't charge them. I never had to worry about parking or money at Basingstoke which is invaluable when going every week. These are all small things but are massive to the patients.

ANSWER: The heartbreaking stories of people who decided not to have treatment because they couldn't face the travelling. A comment mentioned a receptionist - this is important to patients.

COMMENT: There are huge and very good volunteer transport folk who drive people to hospital. There are people who are very kind and will take you. We just need to link everybody up.

COMMENT: I was treated in Southampton and the service was fantastic. All the aftercare and support I had was from Macmillan. My family was looked after by them as well. Having a cancer unit with support from Macmillan or one of the other cancer charities is so important.

ANSWER: We have a great relationship with Macmillan, and all cancer charities like the Pink Place and Ark are so important. It's about the whole care - nutritionists and physios and psychological support. It is about the longer-term relationship with people.

ANSWER: Whilst we have a focus on developing clinical facilities, as part of this we would want to provide a supported care environment. It's important we design and create the right environment for patients and families to spend time because visits to hospital can take a long time. We completely recognise the issue of transport. Our vision is likely to involve a separate entrance with appropriately dedicated parking very close to that. Like many NHS buildings, they were designed

when people didn't drive to hospital. The most commonly complained about issue even when I was studying at medical school 20 years ago was parking.

ANSWER: We do recognise the value and importance of the supportive element of care alongside the medical treatment. Making sure we link in with our primary care colleagues is key as well. Supportive care also includes our primary care partners and charity partners who provide fantastic support for many patients. We need to work as a whole system.

ANSWER: Primary care is changing around this too and we're talking about supportive care. It needs to link up where we're working together so we can have a more coordinated approach and work with our local voluntary teams. We need to join up locally and then link back to hospital treatment.

QUESTION: The support is really important both pre and post care. Post care - you're going to hospital on a regular basis. They know you as an individual. When your treatment is finished you're suddenly feeling like you've been cut adrift. The cancer charities are marvellous but they don't know your history in the same way as the staff in the hospital do and the people who had been looking after you. It's a strange feeling.

Pre-care - it took months for my diagnosis. I was being passed from one department to another and everybody was marvellous, but I really felt alone. I would ask that the holistic view is taken about where support comes in and is provided.

Your emergency line for the emergency questions was absolutely brilliant - you are treated very well. Please don't lose that.

#### **Chat download anonymised**

I agree about isolation needs having spent 4 months on Wessex in isolation!

Having to walk through main hospital when an inpatient on Wessex and neutropenic was terrifying. Just getting into a lift to get to ward as too weak to walk up stairs. Access should be direct and on ground floor

We are looking for ideas on improving cancer services. We must not forget those things that we do well and do not want to change.

Care has been outstanding, this must be celebrated and carried forward. Of course there are challenges and we will learn from those.

I think chemo in a small close to home location is key. I had wonderful treatment from Luke Nolan and his team at Winchester and feel a lot of travel would impact negatively on my outcome

Yes perhaps small hubs

Important not to lose what is good now. Treatment living in Basingstoke, the radiotherapy unit is brilliant, parking easy. When attending every day, this was wonderful. Must not lose these positives!

with regard to "principle of our vision" as well as working closer with social care services which should be joined up and provide continuity this approach should also extend to community cancer charities.

Agree we need better chemotherapy environment. Staff also under greater pressure, individually lovely but lots of delays and rushing about.

DTC at Basingstoke also a great resource. Lack of receptionist only criticism. Otherwise superb, facilities and staff.

The Pink Place is brilliant - must include in your partnership!

To include heart sparing radiotherapy and more new radiotherapy machines like

Thanks XX - The Pink Place appreciate your thoughts

I met with a cancer nutritionist at Winchester and took good advice from her which aided the feeling of having a level of control over my recovery - well worth doing - NB this was 6 years ago

A chemo suite that has reclining chairs instead of beds

Cancer facilities that are geared up for disabled persons

Cancer services that are future proofed for the changing and growing population

When you design the inpatient facilities for haematology patients please could you involve the patients in the design and not just the clinicians? As a nurse as well as a patient of 16 months in isolation on Wessex hat I would have thought patients needed was by no means always what I as a patient needed.

The new cancer hospital to be based near the largest population like Basingstoke

XX's care and support has carried on throughout whole of the current Covid situation

The provision of the latest scanning diagnostic equipment

IT-my care is shared between SOTON and HHFT but often my blood tests for example have to be duplicated because you currently don't share IT path results.

Looking at your principles, what will your criteria be to decide what can be delivered at home, and how far it is reasonable for people to travel? What weighting will you give to clinical, economic, patient experience - and the cost to patients (so economic factors may involve clinician time and travel, but do they include the patient's cost?)

Space for AHP's is really important as find space to see outpatients is a massive issue

Thanks Alex, Lara, Charlotte and Philippa for your presentations, and for outlining this really positive blueprint for future care and support for cancer patients and their loved ones. I'd encourage everyone to give the Hampshire Together team their feedback so everyone is clear how important a new cancer treatment centre and enhanced cancer care

and support is as part of the wider new hospital picture. Supporters at Ark and other local charities are keen to do all we can to support this crucial new chapter in local healthcare.

Pre Operation services provided in a hub form so a group of people see all the doctors, nurses, physios, dieticians, anaesthetics etc on the same day

Yes XX agree

Lara Alloway - CMO HHFT: we would be very keen to have your insights, especially when we get to the design

definitely family support and younger patients with cancer in general

XX totally agrees that it was so important her family were close. Basing unit facilitated me - her mum- to be close at all times however bespoke facilities needed

starting cancer treatment was very daunting, and felt there should be a separate waiting area for new patients as hearing discussions from those who are terminal was very distressing of course I felt very sorry for them and don't want to seem unkind but just feel when starting the journey emotions are all over the place and thoughts and fears are running riot and I know others felt the same. Also feel more time should be spent going through treatment etc explained in non medical jargon and abbreviations beyond that at the initial diagnosis

XX, we will be looking at the Macmillan Quality Environment Mark as a tool to create the environment for the patients.

Seeing a physio and doing exercises before surgery is beneficial to recovery and can be done at the pre OP stage

Will there be other forums - not online - for the elderly members of our community? Appreciate that's difficult during Covid.... People are living longer so we need better provision for them aswell.... don't have their wards on the top floor.

A Day ward attached to the Radiotherapy and chemo unit for patients who become ill during their weeks of treatment.

If you receive excellence in care and environment- and public transport, parking- travelling a distance is ok

Are your documents available in large print please? We've been asked by one of our CSP members.

Engagement Support: HI - yes I will be in touch

pre op assessment is a really good point and something I feel we could improve.

Technology attached to sanitisers that either speak a message that it has not been used to make sure people are hygienic

Southampton Hospital have a 24/7 MAOS team (sponsored by Macmillan) of clinicians and a telephone number and a ward devoted to cancer patient emergencies - patients don't have to go to the normal A&E like they do at Winchester.

Specialist cancer post OP recovery room that has technology that tells the staff when changes are happening with the patient. My experience was very good as staff had more information quickly

Will the new cancer treatment centre be a 'green/eco-friendly' building? Sustainability is so important.

Support and care should not end at the completion of treatment.

Alex Whitfield - CEO HHFT: Absolutely. The national scheme requires that the buildings are carbon neutral but we would want to do that anyway!

Lara Alloway - CMO HHFT: I completely agree, support should also be for living beyond cancer

We (the dietitians) agree that pre-op assessment is vital, and equally post treatment support (pre-hab/re-hab)

definitely agree about separating newly diagnosed patients from patients with secondaries. I was admitted with neutropenia after my first chemo and was scared witless by the patient in the next bed to me who talked about her "final years".

A car park that disabled persons can actually use and is also built to accommodate the growing number in the population who are having treatment together with their relatives. so future proofed too.

To build a community of cancer patients to help each other through treatment. put them in touch with each other.

completely agree XX [comment immediately above]

charlotte.hutchings GP and CCG clinical lead: Completely agree XX [comment immediately above]

XX feels some thought should go into facilities and support for that age group that steps away from child/ young adult to being beyond 24 years old. Its out there however not obvious.

The new cancer hospital could be attached or linked to a cancer research facilities so new drugs could be available where appropriate

better use of the voluntary sector - facebook groups, support groups - people who have been through the treatment are in a better place to offer advice of the practical matters.

Emergency line so reassuring

Will the new Cancer treatment centre be in a unit within the new hospital or will it be in a separate building next to the new hospital. This might help if we have another situation like what we are going through now with Covid-19

As a clinician the MAOS at Southampton works really well

can you add XX as she was unable to attend today. thankyou

Engagement Support: thanks XX - I will be in touch with her myself

If you wish to discuss experience any further off line please do contact us

There should be a list for patients to inform them of everything available for them during and after treatment

Cancer diet friendly cafe

Alex Whitfield - CEO HHFT: we hear your point about the benefits of a separate building - thanks!

Thank you Alex

Alex Whitfield - CEO HHFT: really important about facilities for younger people. Thank you.

Thank you for arranging a session specifically about cancer.

charlotte.hutchings GP and CCG clinical lead: we recognise the need to work together with our support groups and resources in our communities

Dedicated cancer staff in all depts of all new hospital

Thank you very interesting

thanks

**Report written by:**  
Sian Elmslie