

Clatterbridge Cancer Centre Listening Event Report

Thursday 14th September 2023



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Introduction

On Thursday 14th September 2023 Healthwatch Liverpool held a Listening Event at Clatterbridge Cancer Centre in Liverpool. We spoke with patients, family members and staff and listened to what they had to say about their experiences. We wanted to find out what people thought was good and what they thought needed improving at the hospital.

This visit was part of our ongoing programme of visiting local health and social care providers and was a welcome opportunity to make our first official visit to the new Clatterbridge site following a period where we were unable to visit due to Covid-19 restrictions and national guidelines. We are pleased to have this new hospital in Liverpool and we know it makes a significant difference to Liverpool patients who no longer need to travel to the Wirral to access the specialist services provided.

Four members of Healthwatch Liverpool staff took part in the event. We spoke with people in various areas across the building and made them aware that there was no obligation to speak with us and that everything they told us was voluntary and anonymous (unless safeguarding issues were raised that we were required to share with staff). Given the nature of people's treatment, not all patients or family members were willing or able to speak with us and we used our judgement about who to approach, as well as checking with staff on wards about whether anyone was too unwell to speak to us.

14 surveys were completed with patients. Family members also provided additional feedback in some cases.

This report details all the feedback gathered on the day, and also includes our own comments and observations.

Thanks are due to the many staff at the hospital who took the time out of their busy schedules to welcome us and speak to us so openly. Thanks, in particular, to Julie Gray (Chief Nurse) and Nikki Heazell (Head of Patient Experience) for all their support prior to the visit and on the day itself.

Thanks are also due to the patients and family members who agreed to share their experiences with us on the day.

We were also introduced to several members of staff including the Freedom to Speak Up Lead.

We were shown around the building to get an overview of the layout and we also visited the Winter Garden and the Blackburne House café.

We spoke to patients on Ward 2 and Ward 4 but were unable to visit Ward 3 and Ward 5 for reasons of infection control. We also spoke to patients in the Radiotherapy waiting area.

The building's environment felt light, airy and calm, and it was clean and well-maintained throughout. It was explained that floor coverings were due to be replaced in some areas due to the flooring materials being faulty and becoming visibly marked.

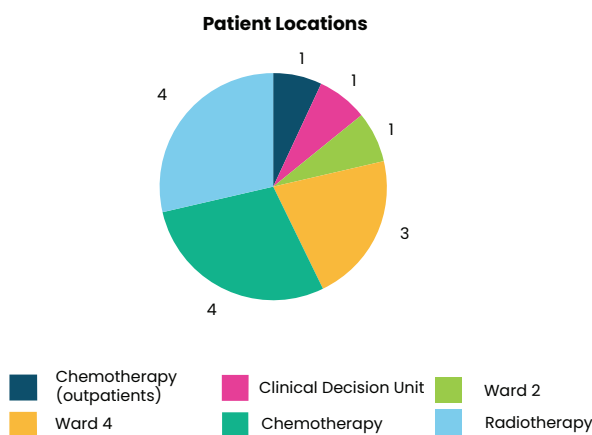
We saw information on screens around the hospital about how to contact PALS (Patient Advice and Liaison Service) as well as information about the Healthwatch Liverpool visit and why we were on site that day. Information was also available about forthcoming industrial action and what to do if it affected existing appointments. Information about shuttle buses was also

available, as was information about car parking and validation for free parking. The café and vending machines were easy to find, as were the beverage bays which offered the opportunity to access free drinks.

In the Radiotherapy waiting area the information screens were clear about who was being called and where they had to go, although it was not clear whether additional methods were used to notify patients who were unable to see or read the screens.

Survey responses

During our visit we spoke in depth to 14 patients who had travelled from across Liverpool, the Wirral, Warrington and West Lancashire.



1. What is good about Clatterbridge Cancer Centre?

Responses to this question can be broadly grouped in the following two categories.

a) Staff attitude and treatment

“They’re kind, caring, you can ask questions, you can ring them on the 24-hour helpline, it helps when anxious. They’re wanting to help. Very friendly staff.”

“The staff are amazing.”

“Everything is superb. They’ve made me feel a thousand time better. Love, kindness, friendliness, expertise, gorgeous – that’s how I’d describe it here. I’m really, really grateful. You couldn’t get better anywhere else.”

“The people are all great. Even the cleaner who comes in first thing in the morning, she’s so smiley and lovely. From the smallest to the biggest thing, everything is great. Everyone is working so hard to sort me out, so I’m very relaxed about it.”

“The service here is pretty good. The staff are good, they’re working well.”

“Everyone’s nice. The staff are amazing.”

“The people are so friendly, they’re absolutely fantastic – even the tea people, it’s as if you’ve known them for years. The service you get from them is great. I’ve been in about a month now, I’m so glad they’ve put me here.”

"Everything's gone well. They look after me really well. I'm happy with everything."

"I've had about 8 visits here, for scans and chemo. Everything is good - the staff are lovely, there's no trauma, it's peaceful, organised, professional. The staff just have an air about them - nothing is too much trouble."

"There's nothing negative about it. The people are great, it's fantastic. I get what I need."

"The staff and the service are very, very good. You feel as though you're being looked after."

"The people are fabulous - nurses, doctors, everyone. They're top notch."

"It's very good. Well organised."

"Everything. Everyone is so attentive. The facilities are spot on. Even Reception. It's the best! They can't do enough for you. I'm just made up that we get this sort of service. It's all good. I've been here 5 days a week for 6 weeks."

"It's very, very good."

"They're friendly and informative."

b) Environment, Location and Catering

"It's well illuminated, natural light, good ambience. The chairs are very comfortable, I work for the NHS and that's not always the case."

"It's very clean."

"The location is very convenient, especially compared to the Wirral."

"I have a lovely room. It's peaceful, calm."

"It's clean, well-organised."

"I was in (another hospital) before - and thank goodness I'm here now. It's heaven here - much more quiet and peaceful than other hospitals."

"The food is good."

2. What could be improved?

Responses to this question included some who felt their experience couldn't be improved, or who were reluctant to make any suggestions.

"Nothing." (This answer was given by 3 people)

"Nothing, it's been perfect."

"I don't want to say anything, it's nitpicking. I don't want to complain after all the care they've given me."

“Not really – they’ve got the best of everything here.”

“I can’t fault it at all. Never had a problem with it here.”

Other responses covered the following categories:

Communication

“Apart from today it’s gone very smoothly. Apparently there’s a problem with the (radiotherapy) equipment or table but they haven’t told us exactly what’s happening, so we’ve been waiting for an hour. They could say there’s been a delay. I’ve got another appointment here today and it would be useful to know how long I may need to wait here.”

“The appointments are a little iffy – sometimes they change at short notice, sometimes I have to chase them up, sometimes I don’t get the appointment details until I get home.”

“Getting through on the phone the first time I called was frustrating – I was just going round in circles. I have the right numbers to call now, so it’s been much easier since.”

“I found out through my son that I’ve got a Link Worker allocated to me – but I wasn’t told about it directly. My son had to be pro-active in contacting them. I think they’re missing a middle management layer to coordinate everything. I have a one-to-one every week but it’s always different people and different discussions. It’s not patient-orientated. Each individual action is very good but it’s not linked up. It’s a process. It’s focused on treatment not personal care and interest.”

“Good information is a key element for all aspects of treatment.”

Accessibility

“A better drop-off point for taxis for patients who are less mobile.”

“Closer parking could be good – it would be a struggle to get here if you were very unwell. I’ve not used the shuttle bus, but I don’t understand why they don’t just build parking onsite for new hospitals.”

“Transport. Mainly taxis. Sometimes you have to wait a heck of a time. It’s haphazard since the kids went back to school. I had to wait an hour and 15 minutes to get home.”

Catering

“The food – it’s made somewhere else, then bought here and reheated. It doesn’t taste great.”

“The canteen is expensive.”

“I’d like to be able to heat drinks in my room – something to make tea with, or heat up some milk – there’s a place on the ward you can make your own drinks, but you’ve got to walk to get it yourself. The nurses will get you a warm drink, but I don’t want to have to bother them for it.”

Environment

"The chairs for patients could be comfier."

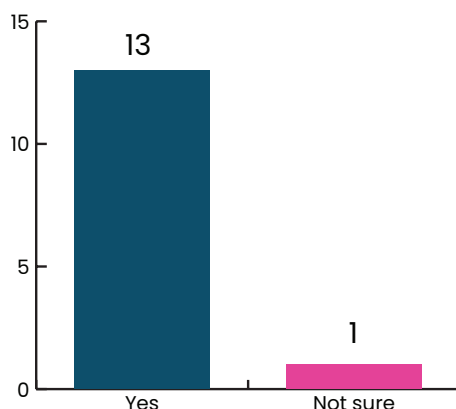
"I would like a TV in the room that works – the TV in here jams all the time. I was told it's something to do with the work at the old Royal, which is a shame because it's a great TV otherwise. It's happened to other patients too."

"I'd also like to be able to control the lights – dim them, or turn them off – from my bed, I don't want to ask staff to do it."

Staff Attitude

"It's mixed. In Radiotherapy there's always different staff. There's no consistency and the people don't introduce themselves. They could say "How's it going for you?" but they don't. One day there were 6 young girls in the room and I had to take my trousers off. I found it embarrassing. But they're all friendly and pleasant."

3. Do you feel that staff have enough time to spend with you and your family/friends?



13 of the 14 respondents felt that staff did have enough time to spend with them and their loved ones.

1 person said they weren't sure. Nobody said 'No'.

Additional comments included:

"They try their real best, but people are multi-tasking. Staffing levels could be improved, but it feels safe."

"They are responsive, as a patient I haven't felt impacted. I've never been left."

"I see them go up and down past my door – I've no issues with the staff at all, I have a great respect for them. Sometimes they are busy, but it's not been a problem for me. You can't beat the staff here, they are amazing."

"They make sure everything is right, they really look after you."

"The staff are extremely good. Some staff come into my room for a little chat, and I really enjoy that. I've made friends with one of the porters as well. He always pops in and says "Hi" when he's here."

"The staff are always really good. You can see they are busy, but they still always check in with you, they're proactive."

"Staff are sometimes run off their feet - you can see it, watching them. They're always there if you need them though."

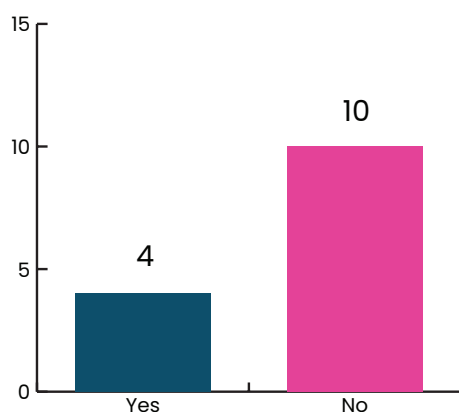
"It's been very good. I've never had to seek out any staff, they're always here."

"They give me all the information I need."

"They always ask what you need in any department."

"They're not seeing the person or the trauma. I'm fitting into their delays and their process. I don't want to undermine them as I imagine they've got a lot to do. I don't feel it's patient-led. I'm anxious about my diagnosis and on a lot of medication and my mood's affected. I'm worried that my treatment may be stopped. It doesn't feel that there's someone taking care - just lots of numbers of contact people with no personal touch. It's difficult to be pro-active when I'm fatigued and feeling sick."

4. Does this apply to both day and night staff (if applicable)?



10 people said this was not applicable in their cases. The other 4 said that staff were equally able to spend time with them during the night as they were during the day.

One person added:

"They'll come if you ring your buzzer for anything, but I don't want to mither them."

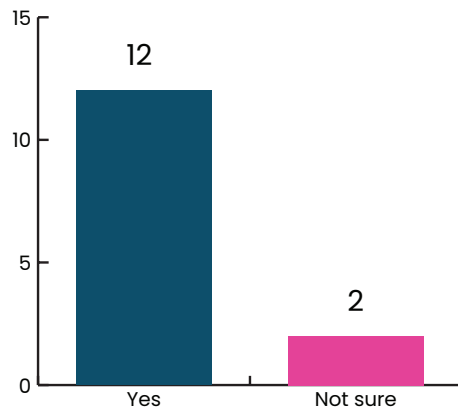
5. Staff attitudes

Staff at Clatterbridge Cancer Centre...

Staff at Clatterbridge Cancer Centre	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Unsure	Doesn't apply to me	Response Total
... treated me with care	0	0	0	1	13	0	0	14
... behaved professionally	0	0	0	1	13	0	0	14
... respected my dignity	0	0	1	1	12	0	0	14

When asked whether staff treated them with care, behaved professionally and respected their dignity, respondents were overwhelmingly positive, with 93% strongly agreeing that they were treated with care and that staff behaved professionally. 86% felt that they were treated with dignity. Nobody disagreed or strongly disagreed with any of these statements.

6. Do you feel involved in discussions around your care and treatment options?



12 of the 14 respondents (86%) were happy that they were involved in discussions about their care and treatment, whilst 2 (14%) were unsure. Nobody said they were not involved in these discussions at all.

Additional comments included:

"I'm better if I don't know too much of the details, and they respect that."

"The information is there to hand, and for family too."

"Yes, and I feel comfortable asking staff more questions if I need to." (While we were in the room, a nurse came round dispensing medication, and the patient asked her for some clarification about treatment following discharge - the nurse was able to give a response the patient was satisfied with.)

"Yes, I'm involved in discussions with the consultants."

"In my assessment prior to chemo, they asked me what I wanted to do and offered me alternatives. You get options."

"I've been involved when I've needed to be involved. If I ever need to ask anything, I can ask them."

"The doctors have kept me particularly involved - I was given a choice of what drug I can take."

"The Dental Hospital, Aintree and Clatterbridge Cancer Centre are all communicating well about my treatment. They work hand in hand. I love the NHS!"

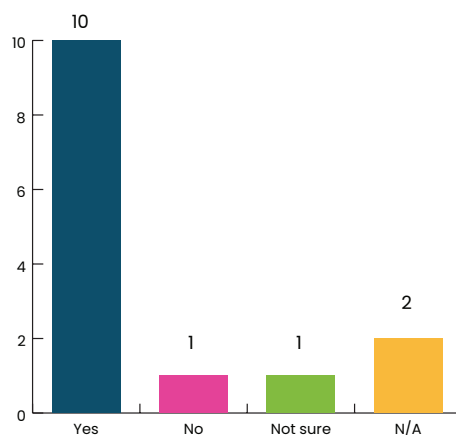
"They talk us through it and explain everything. I couldn't have got better treatment if we'd gone private. We're all in the same position here. They're nice people - the staff and the patients. Plus, there's good views!"

“Managers should be asking staff “Who’ve you contacted this week? How are they feeling? Anything we can do to help?” I think I’m involved but I don’t have a say. They check that I’ve comprehended but there’s no discussion of other possible options. I don’t feel confident about challenging them. There’s a lack of consistency. I don’t know what my rights are except to take what’s offered and sigh with relief that they’re doing something.”

7a. Has the hospital given you enough information during your (or your loved one’s) treatment?

100% of the 14 people who answered this question said they had been given enough information about their treatment.

7b. Has the hospital given you enough information to support you after your (or your loved one’s) treatment?



People were slightly less sure that they had access to all the information they needed to support them once treatment had finished. Nevertheless, close to three quarters (72%) felt satisfied with the amount of information they had access to. Additional comments included:

“I’ve got a clear idea of the next steps.”

“All the information you need, they give, including phone numbers for support.”

“The cancer I have is very rare, they have very little information about it. I had a discussion about it with my consultant, who hasn’t seen anyone with it before. They’ve always been upfront about, don’t sugar coat anything. I’ve called the hotline as well, post-treatment – they answered right away. I rang to ask about what non-prescription medication I can take, I just wanted to make sure it would be okay.”

“They tell me everything before they do it. I’ve used the helpline once too – they put me onto the right people.”

“I was given a helpline number. I rang once in the night – they told me to ring 111 and ask for a doctor to come out to see me. I didn’t feel that was very helpful – I just got a call back after 2 and a half hours and was given a prescription.”

“They’re honest with me about what might happen.”

“I’ve got dates up to November for pre-op treatment. The whole pathway is on my calendar. They’re on the ball.”

“I know that I’m due an MRI test in 3 months. But I want to know whether I’ll feel better and able to work. It’s very uncertain and I’m not getting sufficient answers. I’m left feeling that when the treatment stops I don’t know whether they’ll stay involved. I feel very grateful and I don’t want to seem ungrateful for this expensive treatment. But trying to get through to someone to talk and getting a voicemail saying “Please leave a message” is off-putting.”

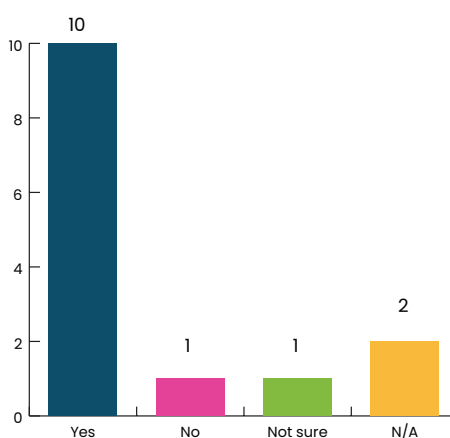
“What happens next is unknown. It depends on what happens with my treatment.”

8. More specifically, has the hospital given you information about support for:

More specifically, has the hospital given you information about support for:	Yes	No	Not sure	Response Total
Physical health worries	8	5	1	14
Mental health worries (e.g. stress, anxiety or depression)	8	5	1	14
Money worries	8	5	1	14
Relationship worries	7	6	1	14

Although the majority (57%) of the patients that we spoke to had received information about sources of support for a range of issues there was still a significant minority who had not or were not sure. In the case of relationship worries the split was 50/50.

9. Would you like more information about any of these?



The responses to this question broadly reflected the answers given to the previous question, with most people feeling they had enough information but some feeling that they would benefit from more.

The respondents were all offered the opportunity to share their contact details if they wished to receive any additional information. Some also made further comments, including:

“I was given information, leaflets. They haven’t discussed it actively and I haven’t asked. The desk downstairs [staffed by people who can provide more information] hasn’t been mentioned.”

“I’m under the centre in St Helens – I’ve been given all of that information there. They haven’t told me about this here in Liverpool, but I assume it’s all here for those who need it.”

"I have a social worker outside the hospital, who will help me with these things when the time comes."

"They've got the Macmillan downstairs, where you come in - they're dead helpful. They signposted me to Maggie's."

"I know there's an information desk downstairs and I've got Macmillan cards but I haven't needed them. But no one's specifically told us about this. A specialist told us that my partner could attend too."

"No. I just want to say that signposting and information packs at the start of treatment are too much to take in. I'm on pain meds and it wasn't done at my pace. They don't check again to see if it's comprehended and retained. Follow-up care and consistency are needed. And more information about the role of the Key Worker. I'd also like to know more about treatment timeframes and aftercare."

One patient said they didn't know where to get this information and the nurse dispensing medication, who was in the room when this question was asked, said that staff could signpost or refer the patient to appropriate information and support.

10. Catering/dietary requirements

If you've had food and drink at the hospital:	Yes	No	N/A	Response Total
Are you happy with the quality?	6	3	5	14
Is it suitable for your dietary needs?	8	0	6	14

Not everyone we spoke to had sampled the food available at the hospital but, of those who had, two-thirds (67%) were happy with the quality and 100% felt it was suitable for their dietary needs.

Additional comments included:

"They come and offer food but I can't eat because of the nausea."

"The canteen food downstairs just isn't great. I got a toastie recently that was basically just warm bread, not actual toast."

"I've not been able to eat anything really - I had some ice cream today, that was maybe the first thing I've had here. I perhaps would have liked some more flavour - this is vanilla, something like Neapolitan would be nice."

"The food isn't what I'm used to - I prefer to cook my own stuff, and not everything I want is available here. They do ask you all about your dietary needs, they are good with that."

"Yeah, the food is alright."

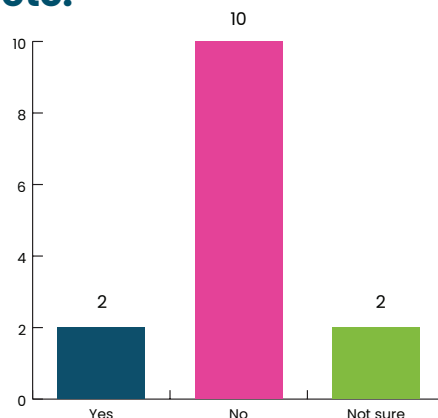
"What they offer is good enough. I get lots of snacks - I don't like big meals."

"I like the little kitchens."

"Tea and coffee is a nice touch. And the sweets on the reception desk."

"I do know about the beverage bays."

11. Could the hospital improve communication with you? If yes, what could be improved? For example letters, leaflets, text reminders, other languages, BSL formats, etc.



Most (72%) said they didn't think the Trust's communications with them could be improved. 14% said there could be improvements, and 14% were unsure.

Additional comments included:

"I have only been an in-patient here, so I've not had letters or anything. The communication in-person is good – so much better than at [another hospital], which is where I was transferred here from."

"Communication is fine. I get letters and texts, and the staff from the immunotherapy team ring me twice a week."

"I was rushed in – I fell several times, I can't recall when. I've been in and out for treatment. I'm not really sure what's going on."

"The issue is with the postal service – we only get post delivered twice a week. The hospital asked me how they could best get in touch with me, so I've told them to text or phone."

"No issues with communication."

"The communication is really good. I had a blood test a while back, they called me back later that same day to say that they needed to do it again for some reason, but I still got the result back that same day."

"They communication is good. They phone me a lot."

"Other than the issue with communication around the appointments, it's otherwise been good."

"I've been late for appointments because my phone wasn't working and I missed calls – but that's not the hospital's fault."

"It's very good. They've just rung me to tell me to go and pick up a letter at Reception."

"Letters arrive after I've already received texts so there's a delay there. Digital contact is easier to organise but contact from the Key Worker would be appreciated."

"It's very good."

12. How accessible do you think the hospital is in terms of a) travelling to it, and b) getting around it (e.g. signage)?

Most people told us that access was reasonably good and that they could find their way around once they'd orientated themselves, and provided they were feeling well enough to. However, confusion about the numbering of floor levels was a particular theme, and waiting for lifts could take a long time. Staff members who we spoke to also recognised this as an issue and told us that discussions had taken place about how to improve the situation. Patient comments included:

"It's easy to find your way around. The lift can be a bit crowded sometimes."

"I haven't been able to get around. The physiotherapist has been helping me with my movement though - they have been brilliant. I can't thank everyone enough."

"It's clear to get around."

"Driving here is easy. They do offer free parking which is great, but the parking for patients is shocking - it's hard to get from the car park. I couldn't do it alone. Once you're in the building, everything is signposted well."

"I've not been well enough to get around."

"It's easy to get around."

"I know how to get around, but it baffles me. Why do you enter on Level -2? I heard it was something to do with linking it up with the new Royal, but it just baffles me."

"It's good - it's easy to get to, and easy to find my way around."

"Time wise, getting here can be awkward. It takes anywhere from 30 - 90 minutes, depending on the traffic. Once you're here, sometimes there can be a long wait for the lift."

"They send me taxis. It wasn't easy to find my way round at first. Having the Ground Floor on Level -2 is difficult."

"Good. But avoid the lift. They should just do floors 1 to 10. The minus numbers are confusing. The first time I used it I was up and down."

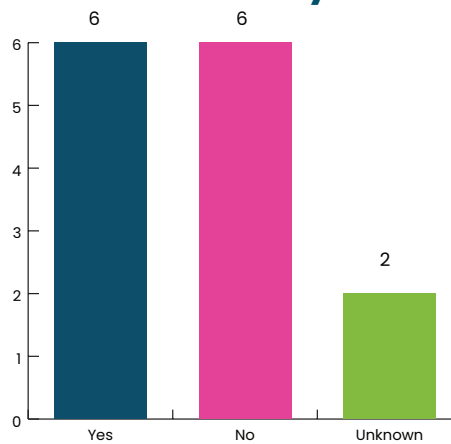
"It's confusing at first with minus floors - but you soon orientate yourself."

"The taxis are very helpful. They're trying to help but it can go wrong. This week they've been 2 hours early OR late and it takes a lot of energy to prepare myself. And they're receptive to moving appointments. The hospital offers a lot of services but I still feel stress and anxiety."

"It's easy but costly. It's cost £1,500 for 3 weeks' taxi fares. The oncology consultant said it can take up most of the day to wait for hospital transport so we decided to pay for taxis."

"The lifts are very confusing. Why is there no 'Basement'? Why not just say 1st Floor, 2nd Floor etc.?"

13. Have you had any remote appointments (phone or videocall appointments) at Clatterbridge Cancer Centre? If 'Yes', did you feel these worked well? Tell us more about how they worked for you if you wish.



There was an even split in responses to this question with 43% of people telling us they had experience of telephone appointments which they were happy with. A further 43% of people had not had telephone appointments.

"I've had some phone appointments - I think they work well."

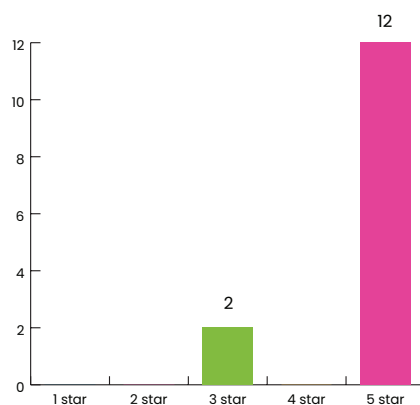
"I've had a few phone calls - they've all worked out fine."

"I had some phone appointments for my previous cancer, when I was under the Women's. They were good."

"The phone consultations I've had have been good."

"I always have a call on Wednesdays. The phone calls go well."

14. Please rate the service here at Clatterbridge Cancer Centre overall:



14 people provided a Star Rating, with 86% giving the hospital a 5 Star/'Very Good' rating. 14% rated the hospital 3 Stars/'Neither Poor Nor Good'. Nobody that we spoke to gave a 'Good', 'Poor' or 'Very Poor' rating.

15. Any Other Comments?

Some of the patients we spoke to made some additional comments, including:

"Sarah the phlebotomist is amazing, a real 'people person'."

"All staff are good, I haven't met anyone where we thought 'oh no!'."

"I would rate them way beyond 5 stars."

"There are a few times staff haven't respected my dignity."

"The male nurses are good around respecting my dignity - I've had three children, I don't care - but they are extremely good. I'm very happy with it here, everyone has been so good with me. I just hope they've been able to get it all [the cancer]. I'll be lonely when I go home."

"I love them for their sensibility, respect, love and humility."

"It's been alright but I'd sooner not be here. I'm only here because of a cock-up at [another hospital] where they misdiagnosed me. I did raise it with them but I haven't heard anything back. I don't want anyone reprimanded but I think they should know about it." (We gave this patient a Healthwatch Liverpool information card and explained that we could follow this up if they wished).

"I'd give it 5 Plus! It's perfect. The girls up here work really hard but they still offer to make a cup of tea. I say they're overqualified for that and I can make it myself but it's nice that they ask."

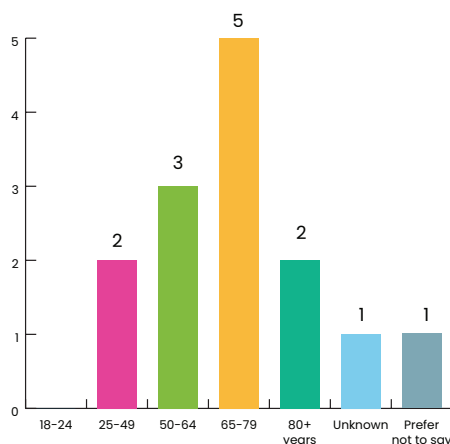
"The pharmacy and blood tests on site are very useful."

"We've found everybody very warm, kind and very friendly - from the young man at the desk to the volunteers. They're all very kind."

Equality, Diversity & Inclusion

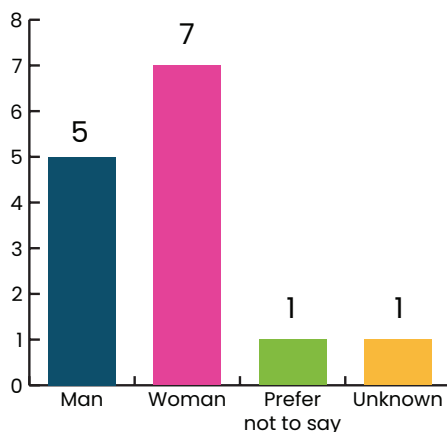
The following questions are designed to help us to monitor any evidence of health inequalities in treatment or outcomes.

A) What age group are you in?



The largest group of survey participants (36%) came from the 65-79 age group. With 22% coming from the 50-64 age group.

B) Gender

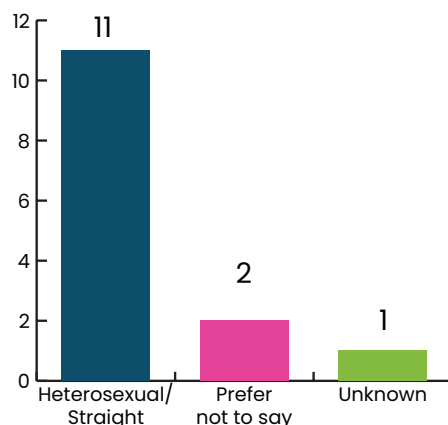


Half of those we spoke to (50%) were women, and 36% men. 7% preferred not to say and a further 7% did not answer this question.

C) Gender identity

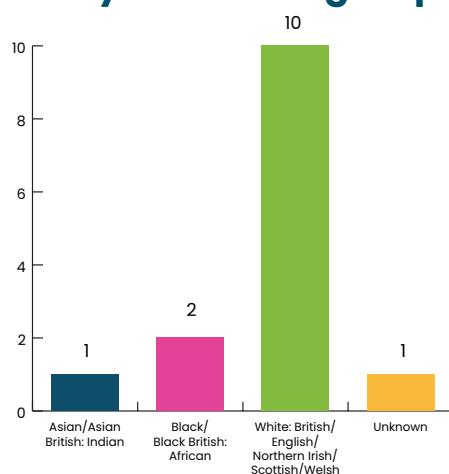
The majority (79%) of people said they identified with their sex as recorded at birth. One person preferred not to say and two did not answer this question.

D) What is your sexual orientation?



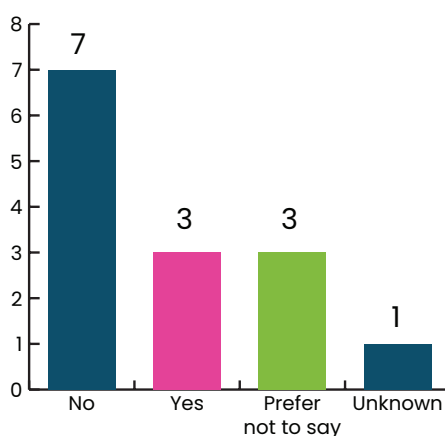
The majority (79%) said they identified as heterosexual. Two people preferred not to say and one did not answer this question.

E) How would you describe your ethnic group?



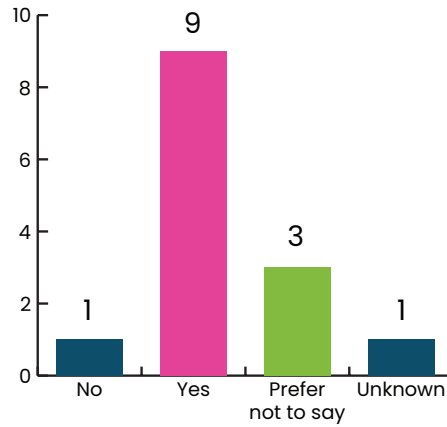
The majority (72%) told us that they were White: British/English/Northern Irish/Scottish/Welsh, with 14% being Black/Black British: African, 7% being Asian/Asian British: Indian and 7% not answering the question.

F) Do you have a disability?



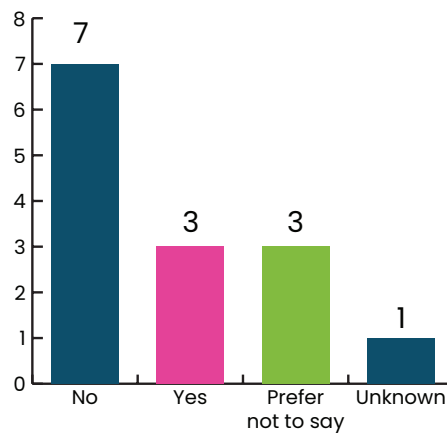
Half of the people we spoke to said they did not have a disability (it is not clear whether they realised that cancer counts as a disability and entitles them to certain benefits e.g. Personal Independence Payments (PIP)) 22% said they did have a disability, 21% preferred not to say and one person did not answer this question.

G) Do you have a long-term health condition?



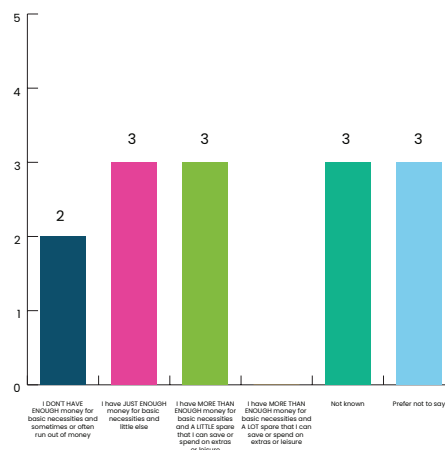
64% of people surveyed said they did have a long-term health condition whilst 7% said they hadn't. 22% preferred not to say and 7% did not answer the question.

H) Do you consider yourself to be a carer?



50% of people did not consider themselves to have caring responsibilities, whilst 22% did. 21% preferred not to say and 7% did not answer the question.

I) Which of the following best describes your current financial situation?



There was a mixed picture in terms of patients' financial situations with 21% saying they did not have enough money for basic necessities, 22% having just enough for basic necessities, and a further 22% having more than enough for basic necessities and a little to spare. Others preferred not to say or did not answer this question.

Additional Comments, Questions & Recommendations – and Responses from Clatterbridge Cancer Centre

Following our visit we drew up the following list of questions, comments and recommendations which we shared with Clatterbridge Cancer Centre. **Thanks to them for their thorough responses which we've included below in bold type.**

1. We were pleased to see that Healthwatch Liverpool information was available on screens on the day of our visit. We would welcome discussions on how we could include information about ways to contact us as part of the regular information seen by patients on a daily basis. We already have QR codes and contact information on display at other local hospital Trusts which generates regular patient feedback that we can then share with the Trust.

We would welcome the opportunity to share QR codes on our internal communication screens for patients and carers to feedback directly to Healthwatch.

2. We were not clear about how patients waiting in e.g. Radiology are called into their appointments if they are unable to see or read the information screens. Further information about this would be appreciated.

The Clatterbridge Cancer Centre has processes in place to support patients who require additional support with communication. Individual alerts are available on the electronic patient record to inform staff of any specific support required. In addition staff members will call patients by name if they are unable to see the screens and our community of volunteers provide additional support to patients where required upon arrival to the hospital.

3. We would be interested to know whether patients are provided with an information pack at the start of their treatment including where/how to access support around issues including financial worries, relationship worries, mental wellbeing and physical health. We think this would be useful for patients/partners/family members if it does not already exist. We believe that all patients are made aware of Macmillan and Maggie's services but are they also aware of Sunflowers and services such as the Live Well Directory?

During a patient's first appointment information specific to the clinical team they are meeting is provided to patients, whilst being mindful to not overload individuals with information at that stage.

A Holistic Needs Assessment (HNA) is a tool which can highlight any potential concerns patients may have concerning their finances, relationships, mental wellbeing and physical health where appropriate signposting occurs. Currently these assessments do not capture all patients but work is being undertaken to improve the offer and uptake of Health Needs Assessments of patients. Information on how to access the Macmillan Cancer Information Centre and Welfare Benefits Advice Service is shared at The Trust Induction Programme, with awareness sessions being held for Cancer Support Workers and Clinical Nurse Specialists about these services.

4. We would also like to know whether named staff undertake regular follow-up 'check-ins' with patients throughout their treatment about whether they have any questions, would benefit from additional advice or support or are having difficulty coping with their situation. Even if this information is provided at the start of treatment it may not necessarily have been remembered or understood when patients/partners/family members have been dealing with life-changing news.

Patients undergoing cancer treatment have regular treatment reviews with a member of the clinical team, where any additional advice or support is provided. In addition we have three cancer information and support centres at Clatterbridge Liverpool, Clatterbridge Aintree and Clatterbridge Wirral. These services offer support to patients, carers, family members and friends, providing information and support around living with and beyond cancer. If any specific issues are raised to the Cancer Information and Support Service Team, these would be escalated to the relevant clinical team with consent.

5. Digital communication with patients generally appears to be working well but we are interested to know more about how the Trust addresses the potential digital exclusion of e.g. older patients, those who do not have good English language skills, or those with sensory impairments. We heard evidence that the Trust uses multiple methods of communication but that relying on postal communication can sometimes lead to unnecessary delays or missed appointments.

Patients are provided with the option to 'opt out' of electronic correspondence. The Cancer Information and Support Service Team, can assist patients with this as can other members of the wider hospital team – volunteers, administrative staff etc. In addition, if the electronic link sent to a patient via digital communication, hasn't been accessed within a set time frame, the information is sent to the patients in a paper letter. Where appointments are time sensitive, patients are contacted by telephone with the details. The electronic patient record in addition highlights any specific requirements which may assist patients for example, such as requiring documents in large print or in an alternative language.

6. We would welcome information about how Clatterbridge Cancer Centre works to support neurodivergent patients and makes them welcome within the hospital environment.

We provide individualised/personalised care to patients. Therefore all patients are provided with support based on their individual requirements. In addition we have a dedicated additional needs practitioner working for the organisation, who is available to provide support to patients and their carers/families whilst in the hospital. Our electronic patient record contains an additional needs assessment supporting the provision of reasonable adjustments for patients and we encourage the use of the hospital passport in addition. All clinical staff undertake the Oliver McGowen training programme as a part of mandatory training requirements.

7. We would also be interested in how the Trust works to provide trauma-informed care to support patients whose past experience of e.g. sexual violence may make intimate care or examinations particularly difficult.

Care would start at a patients initial assessment with staff being aware that advice can be sought from the organisations safeguarding lead to provide advice and support to patients and staff. Level 3 safeguarding training provision encompasses caring for people whom have experienced trauma in their lives. Level 1 safeguarding training provides basic advice to enable all staff to signpost patients to the appropriate support available within the organisation. In addition the Integrated Care Board have facilitated training about trauma informed care which was open to all staff.

8. A common cause of confusion for patients and other hospital visitors was the numbering of the hospital's floor levels. We understand that the floors were numbered to match the floors of the neighbouring Royal Liverpool University Hospital and for ease of patient transfer between the two Hospital Trusts. Whilst it may not be possible to re-number the floors, some additional explanation may help. We recognise that efforts have been made to give each floor a clear identity and that patients learn to navigate the building over time, but any additional information that can be provided to assist patients would be helpful.

We acknowledge that the floor numbering system is not intuitive when the Clatterbridge Centre is viewed in isolation. The floor levels are named to correspond with the floor levels in the Royal Liverpool University Hospital next door. This system supports the transfer of patients between our hospitals as well as our processes to respond in the event of an emergency. We based our wayfinding system on location numbers rather than floor levels to try to lessen confusion as far as possible. Additional signage has recently been installed across the Clatterbridge Liverpool site, with a large monolith now in place in the main reception area to assist patients and visitors with moving around the hospital. In addition, our community of volunteers in the main reception area, welcome and support/escort patients to their destination if required.

9. We would be interested to know what consideration has been given to improved usage of the lifts so that people spend minimal time waiting, and to reduce the need to share the confined space with others when they are immuno-suppressed.

There are 3 passenger lifts available to members of the public, in addition to the main stairs. We also have 2 bed lifts, a facilities management lift and a staff only lift and these are designed to keep the passenger lifts as free as possible for patients and visitors. Even so, at busy times there might be a short wait for the passenger lifts. All patients, staff and visitors have an option of wearing a mask and these are readily available at the main reception area near to the lifts at Clatterbridge Liverpool. If patients require reasonable adjustments to be made for their visit, requiring a larger lift or being around less people for example, then staff will support patients so this is achieved.

10. We were interested that 50% of the people we spoke to said they did not have a disability. We were not clear whether they realised that cancer counts as a disability and entitles them to certain benefits e.g. Personal Independence Payments (PIP) or whether they did realise this but did not want to label themselves as disabled. We would, however, recommend that further information should be provided to patients about this early in their treatment so that they are able to claim any benefits which may help them to cope with changes to their financial situation and/or daily life. This may also be beneficial to people who are currently paying considerable sums for taxis to and from the hospital.

Due to recent expansion of the Macmillan Welfare Benefits Service provision, the team are able to support patients at their point of need. Access to the service has expanded by having Macmillan welfare benefits advisors available across the three main Clatterbridge sites in all of the Cancer Information Centres. In addition the cancer information and support service staff have undergone basic welfare benefits training in order to support patients when they utilise the drop in service operated by the team, referring on for more detailed advice and support as required. The Cancer Information Centre, including the welfare benefits service is introduced to all staff as a part of the Clatterbridge Cancer Centres, Trust induction programme and can be accessed by any patient who is undergoing treatment at The Clatterbridge Cancer Centre, irrespective of how individuals define themselves. Patients are made aware that it is not the label of cancer which entitles them to certain benefits, but the wider impact of living with cancer has on their health and wellbeing.

Acknowledgements

Thanks to everyone who took the time to share their stories, experiences, and information with us. Their contributions were anonymous, but very much appreciated.

About Healthwatch

Healthwatch is the independent champion for people who use health and social care services. We're here to make sure that those running services put people at the heart of care.

One of our main purposes is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

As part of a national network made up of local Healthwatch organisations in every local authority area of England (and Healthwatch England, the national body) our work contributes to a nationwide perspective on health and social care services.

At Healthwatch we also provide an information and signposting service which helps to put people in touch with services and activities that can help maintain and improve their health and wellbeing.

If you require a copy of this report in another format or language, please contact us and we will provide it.

November 2023

Contact

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Appendix A: Survey

Clatterbridge Cancer Centre
Listening Event Questionnaire

healthwatch
Liverpool

1. Are you: a Patient a Visitor Staff Other

2. First part of your postcode (eg L8, L22, L37)

3. Which ward or outpatient area is your feedback about?

4. What is good about Clatterbridge Cancer Centre?

5. What could be improved?

6a. Do you feel that staff have enough time to spend with you and your family/friends? Yes No Not sure

6b. Does this apply to both day and night staff (if applicable)? Yes No Not sure Not applicable

7. Staff at Clatterbridge Cancer Centre...

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Unsure	Doesn't apply to me
... treated me with care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... behaved professionally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... respected my dignity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Do you feel involved in discussions around your care and treatment options? Yes No Not sure

9. Has the hospital given you enough information:

a) during your (or your loved one's) treatment? Yes No Not sure N/A

b) to support you after your (or your loved one's) treatment? Yes No Not sure N/A

10a. More specifically, has the hospital given you information about support for:

i. Physical health worries Yes No Not sure

ii. Mental health worries (eg stress, anxiety or depression) Yes No Not sure

iii. Money worries Yes No Not sure

iv. Relationship worries Yes No Not sure

10b. Would you like more information about any of these? Yes No Maybe

If yes, would you like to share your contact details?

11. If you've had food and drink at the hospital:

a) Are you happy with the quality?

Yes No Not sure N/A

b) Is it suitable for your dietary needs

Yes No Not sure N/A

*Prompt re variety, portion size, healthy options, cultural and dietary needs, cost (if not free).
Are people aware of Beverage Bays (in Outpatients and on wards) – where they can help themselves?*

12. Could the hospital improve communication with you? If yes, what could be improved? For example, letters, leaflets, text reminders, other languages, BSL formats etc.

Yes No Not sure

13. How accessible do you think the hospital is in terms of a) travelling to it, and b) getting around it (e.g. signage)?

14. Have you had any remote appointments (phone or videocall appointments) at Clatterbridge Cancer Centre?

Yes No

If 'Yes', did you feel these worked well? Tell us more about how they worked for you if you wish.

15. Please rate the service here at Clatterbridge Cancer Centre overall:

Very poor 1 2 3 4 5 Very Good

16. Any other comments?

17. Would you like us to contact you about your feedback? *(By sharing your feedback, you are helping to highlight improvements that can be made to local health and care services. If you would like us to contact you further about your feedback, let us know below.)*

Yes – Please share your phone number and/or email address **No**

Name

Telephone number

Email

We will only contact you for the purposes indicated. By entering your contact information on this survey, you are confirming that you consent to Healthwatch Liverpool contacting you for these purposes. If you share your details with us, they will be kept separately from the other information you share here. You have the right to withdraw your consent at any time. All personal data will be stored in accordance with Healthwatch Liverpool's Privacy/Data Retention policy.

Some questions about you *(We don't ask for your name, so any information you give is anonymous)*

Equality, Diversity and Inclusion Monitoring. We ask these questions because it helps us to understand how your life circumstances impact your experience with health services.

18. What age group are you in?

- 0-12 years 13-15 16-17 18-24 25-49 50-64 65-79 80+ years Prefer not to say

19. Are you a

- Woman Man Non-binary Intersex Prefer not to say

Prefer to self-describe

20. Is your gender identity the same as your sex recorded at birth?

- Yes No Prefer not to say Not known

21. What is your sexual orientation?

- Asexual Bisexual Gay man Heterosexual/Straight

- Lesbian/Gay woman Pansexual Prefer not to say Not known

Prefer to self-describe

22. How would you describe your ethnic group?

- | | |
|--|--|
| <input type="radio"/> Arab | <input type="radio"/> Mixed / Multiple ethnic groups: Black African and White |
| <input type="radio"/> Asian / Asian British: Bangladeshi | <input type="radio"/> Mixed / Multiple ethnic groups: Black Caribbean and White |
| <input type="radio"/> Asian / Asian British: Chinese | <input type="radio"/> Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic groups background (please specify below) |
| <input type="radio"/> Asian / Asian British: Indian | <input type="radio"/> White: British / English / Northern Irish / Scottish / Welsh |
| <input type="radio"/> Asian / Asian British: Pakistani | <input type="radio"/> White: Irish |
| <input type="radio"/> Asian / Asian British: Any other Asian / Asian British background (please specify below) | <input type="radio"/> White: Gypsy, Traveller or Irish Traveller |
| <input type="radio"/> Black / Black British: African (please specify below) | <input type="radio"/> White: Roma |
| <input type="radio"/> Black / Black British: Caribbean | <input type="radio"/> White: Any other White background (please specify below) |
| <input type="radio"/> Black / Black British: Any other Black / Black British background (please specify below) | <input type="radio"/> Any other ethnic group (please specify below) |
| <input type="radio"/> Mixed / Multiple ethnic groups: Asian and White | <input type="radio"/> Prefer not to say |
| | <input type="radio"/> Not known |

Prefer to self-describe

23. Do you have a disability?

- Yes No Prefer not to say Not known

24. Do you have a long-term condition?

- Yes No Prefer not to say Not known

25. Do you consider yourself to be a carer?

- Yes No Prefer not to say Not known

26. Which of the following best describes your current financial situation?

- I have MORE THAN enough money for basic necessities and A LOT spare that I can save or spend on extras or leisure.
- I have MORE THAN enough money for basic necessities and A LITTLE spare that I can save or spend on extras or leisure.
- I have JUST ENOUGH money for basic necessities and little else
- I DON'T HAVE ENOUGH money for basic necessities and sometimes or often run out of money
- Prefer not to say Not known