



Healthwatch Lambeth Enter and View Evelina London Kidney Transplant Unit - Enter & View Visit Report

May 2019

About Healthwatch Lambeth



**Healthwatch
Lambeth is the
independent health
and social care
champion for local
people.**

We work to ensure your voice counts when it comes to shaping and improving services. We address inequalities in health and care, to help ensure everyone gets the services they need. We are a charity and membership body for Lambeth residents and voluntary organisations.

There are local Healthwatches across the country as well as a national body, Healthwatch England.

About Enter and View Visits

Our Enter and View programme involves visiting publicly funded health and social care services in Lambeth to see what is going on and talk to service users, their relatives and carers, as well as staff.

Every local Healthwatch has a legal responsibility to carry out an Enter and View programme. However, we are not inspectors. Instead, we focus on what it is like for people receiving care. We provide extra eyes and ears, especially for the most isolated and vulnerable. Our visits are carried out by trained and police checked volunteers, unless they are young people, in which case they will be accompanied by staff.



Visit overview

Service Kidney Transplant Unit
Evelina London
Penguin Zone, St Thomas Hospital.
Westminster Bridge Road
London SE1 7EH

Registered provider Evelina London

Date of visit Monday 18th February 2019

Enter and View Team Natalia Sali (Healthwatch Lambeth)
and four young people authorised
representatives:

Bradley Townsend
Chidimma Nwankwo Soriano
Jaziah Williamson
Naomi Kolawole

Service liaison link Arran Wheatley (CNS Paediatric Renal
Transition)

Fatimah Vali - Patient and Public
Engagement Specialist

Grainne Walsh (Paediatric Advanced
Nurse Practitioner - Renal)

Vanda Fairchild (Young Adult Kidney
Coordinator - Renal)



Executive Summary

Four young people visited the Kidney Transplant Clinic at Evelina London in February 2019. They interviewed 13 people: 6 patients, 4 relatives and 3 staff. They also observed the environment, facilities, and looked at information and communication materials.

Relatives and patients said that the quality of services is excellent and they appreciate the engagement with the staff and specialists. They felt that they are involved in decisions about their care and that communicating with the staff is extremely easy.

Patients and relatives find the staff friendly, professional, and approachable. They said that they would not hesitate to ask any questions.

All respondents said that good quality care and the opportunity to participate are the aspects that matter most to them. It appears that those are being achieved.

It was found that the clinic has a robust mechanism to support young people's transition to adult kidney service and towards independence. Some patients confirmed that they have a few minutes alone with the clinician and can freely talk about their condition without their relative in the room. However, it appears that transition process does not resonate in the patients or relatives. This could be due to the use of language/term 'transition' which might not be that understandable to them.

The staff said that they are happy with teamwork with colleagues and also work with other hospitals. They said that they feel they are listened to and their suggestions on how to improve the service are being considered. They also said that

young people need to be heard and be given opportunity to have their inputs in how the services are provided. They also said that young people's engagement should be embedded in service provision including being consulted on their care and how the environment could be improved.

It was found that the signages along the corridors are small and written only in English. The passageways in the waiting room are also narrow. Nevertheless, the overall environment was found to be welcoming, safe, and well maintained. Basic necessities are being provided and there is a wide range of activities for young children.

There is also access to interpreters which patients can pre-book.

In summary, it was found that the overall experience of care and staff attitude are of good quality. Patients and relatives also felt that they are being engaged in decisions about the patients' care and that they feel they can approach the staff if they need to ask questions.

The four young people enter and View representatives recommended some areas for improvement. First, Evelina London can improve the communication about transition so that patients and relatives will relate the service they receive with the young person's preparation for transfer to adult kidney service. Second, they can make the signages bigger and have some translated in other languages. Third, they need to promote other ways of participation which are already available in the clinic but are not known to patients and relatives.

Purpose of visit

The visit was aimed at understanding how 'children and youth-friendly' the services at Evelina London from the views of patients, relatives, and staff.

The visit is also aimed at exploring the support children and young people receive in preparation for their move to adult kidney service. The visit is specifically aimed at listening to young people who are 12 years old and older.

Location

The Kidney Transplant Unit is located on the Penguin Zone within St Thomas' Hospital Trust. It is well served by public transport.

About the services

The Kidney Transplant Unit

The Kidney Transplant Unit was United Kingdom's first established children's kidney programme, pioneering children's transplantation in 1968 and continuing to do so since then. Children receive follow-up care at Evelina London. The unit is consultant-led team, supported by a transplant clinical nurse specialist and other professionals and has strong links with adult kidney clinicians at Guy's Hospital.

In collaboration with Guy's Hospital, the unit has an active live donor transplant programme benefitting 70% of its patients. The unit also runs the pre-emptive transplantation (without prior dialysis) where possible, and achieve this for around 50% of their patients. They introduced incompatible transplant programme in 2011.

The unit is responsible for transplant services for Southampton Children's renal unit. They also provide transplant services to other national and international centres as needed.

Transition Service

Transition as used in this context is the transfer of young people between 16 and 18 from children's kidney services to adult kidney services. The process is a planned gradual and starts when the child is 15 to 16 years old although the doctor or nurses can talk about it even earlier. It involves discussion of the patient's health care need as an adult, the choice of hospital or services to best suit the needs, and ensuring that the young person is prepared for the move.

At the transition stage, the clinic provide coordinated care in which young people and parents or carers are fully involved and share the decision making. Evelina London employs a Young Adult Kidney Care Coordinator who ensures that children have smooth transition to adults' services.

Methodology and participants

Four young people aged 16 to 17 who have been trained as Enter and View representatives conducted the visit and interviewed 6 patients, 4 relatives and 3 staff. They were assisted by Evelina London's staff and was supervised by Healthwatch Lambeth staff.

A briefing was held to discuss the services provided at the clinic and the roles of the staff. There was a discussion on the transition service and how the children and their parents/relatives are engaged in planning about their transfer to the adults' kidney service. There was an opportunity for the Enter and View visitors to ask questions or clarify aspects of care and interaction with patients.

At the briefing, the representative from Healthwatch talked of the aims of Enter and View and the focus of the visit. It was agreed that interviews would be with young people who are transitioning to adults kidney services. The Young Adult Kidney Care Coordinator agreed to

identify the patients and relatives and ask for their permission before they are referred to the interviewers.

Interviews were held in private rooms, with each interview lasting for up to 20 minutes.

The unit became busy towards the middle of the day and it was decided to finish the last interview at around 12 noon. A short debrief was held where key findings from interviews were presented.

Findings

The physical environment

It is felt that the clinic is accessible as there are labels around the hospital marking where to go although they could be confusing for some. During the visit, we were accompanied by one staff from the GSTT engagement team. It was observed that there are many passageways to go through. The signs are also written in English which may not be accessible to people whose first language is not English.

Waiting room

The room is welcoming with good lighting and child-appropriate decors. The floor is clean and there is a wide selection of comfortable seats. However, it can also be small in proportion to the patients and relatives during busy hours. The passageway is also narrow.

The waiting room offers a wide range of activities for younger children including children's books and games. There is also free Wi-fi but not enough sockets and they are not visible. There is enough water supply.

Staff call patients in the waiting room if it is time to be seen by clinicians. Staff are friendly, approachable and smiling. Privacy is also maintained once the patient is called as there are enough

rooms with doors and so, private conversations cannot be overheard outside.

There are some leaflets and posters including transition leaflets. There are also books, toys, and games for young children. However, there is less activities for young people and none for parents.

Others

There is a spiritual room on the second floor but is not clearly signposted from the clinic. There are only a few toilet cubicles. At the time of the visit, the floor was wet and there were no sanitary items available.

We asked patients about food in the clinic. Some said that it is not too bad and there are different options including vegetarian. Some also said it is horrible but that one can expect in a hospital setting. One patient said that they go out to eat in a good restaurant.

Findings from interviews with patients, relatives, and staff

A typical day at the clinic

Patients described their typical day which starts with blood and urine tests and height and weight measurement. As they wait for the results, they play games and do art and craft which they find enjoyable. The only concern is the very long waiting time for tests results.

They said that they receive good care and that the doctor explain their condition. Depending on the test results, the next visit is scheduled. Because they visit the clinic regularly, some of them have made friends. They also appreciate that visitation is allowed.

Staff told us that they see up to a hundred patients each day. Young people

get their blood tested first by 11 am. They will have up to 5 minutes on their own with the nurse. There are also other professionals such as play therapist, social worker, psychologist, and pharmacist.

The clinic offers specialist service and patients have frequent visits after the transplant, some up to three times a week. They said that Guy's Hospital and Evelina work together to align services. Young adult transfer either to Guy's Kidney Department or St Thomas' outpatient and inpatient.

Staff said that they work with everyone who are at any of these situations: pre-transplant, undergoing dialysis, patients from Great Ormond Street Hospital, and 14 plus patients who are seen in the teenage clinic.

One staff said that she believes she can help achieving their health outcomes; positive impact on their health; and introduce independence at young age

Overall experience of care

Patients and relatives said that their overall experience of care and the interaction with all the staff are good. They receive feedback from doctors and they can also ask questions. They said that the staff are understanding and friendly and everyone is nice that they don't get bored.

They value that doctors will try to see them as soon as possible. They also give advice and explain their condition. They are referred to different specialists and can access different doctors. The staff are quick and responsive to their needs. They can't say anything bad about the treatment they get.

They also said that all staff are supportive to them and they treat them like their own children. They are also polite, very professional, and accommodating. They are also kind, caring, and some are funny. They feel that they can go to anyone to

ask question and they would have useful answers. They ask questions about diet and about their condition and they get the answers from the relevant professional.

The young people value that they are involved in their care. They are given information and the treatment plan is explained to them in clear and understandable way. Clinicians also update them regularly and they feel they have enough information about choices.

What matters to young people

We asked young people what is important to them. They said that hygiene and spacious area, good treatment from staff, and enough guidance from doctors to avoid confusion about their condition are the things that matter to them. They also said that it is also important that they can share opinions. When asked how they do this, they said that they complete a questionnaire, can talk to consultants, and they receive regular emails.

Staff's responses also reflect what young people had said. They said they think young people want to be treated normal and as individuals. They want to feel supported, respected, and valued. They also want to be able to speak about things and be able to express themselves. They said that young people want that the issues they deal with be treated with equal priority.

Interestingly, staff mentioned a number of ways by which young people can be heard but none of these were mentioned by the patients and relatives. For example, they said they communicate via WhatsApp chats, survey, one to one interviews, Ready steady go questions, focus group with young people, tweeter account, and via suggestion boxes. They also said there is a forum for young people to express their views and feedback. In addition, they said that there is transplant choir where someone

will go into waiting room to throw out questions. Patients can take part in sports activities (e.g. Transplant Olympics). They communicate and call them when they missed appointments.

Accessible information

Staff said that there is additional help for those from different ethnic background who can't speak English. Patients also confirmed that interpreters can be pre-booked.

Staff said that there are useful online resources made via GSTT and those can be shared more widely to better inform young people. They also said that they write clear clinical letters to those young people at the age of 16.

Preparation for Transition

We asked the patients about the preparation for their transition to the adult ward. All of them said that support with transition has been mentioned once but that they have not talked in details. Nevertheless, they said that they are given five minutes to talk to the staff alone (without their relatives).

Confidentiality

Staff said that they have a robust policy on confidentiality. Serious concerns about mental health are referred to a specialist. They also have clinical governance and rules and guidelines about who can give evidences, which is part of their role.

The above resonated in patients' responses. They said that they feel safe and they are treated with dignity. They also feel that their privacy is respected. In addition, they said that they feel safe because the receptionists would not just let anyone through without proper identification.

What can be improved

When asked if there is anything they want to change, all patients and relatives said that the care is good as it is. They said that there could be more appropriate things to do for young people and more activities for young children.

They also want the waiting time to be shorter. One patient travels every week from outside London and said that there is nothing that can be done about it. He just wished that there was a good specialist clinic nearby.

Equally, the staff also felt that there are things that can be improved. They said that there is no separate area for young people and the waiting room can be bigger. The child zone used to be available but they don't have it now that they have moved inside the main St Thomas' Hospital. They appreciate that there is pressure in resources. They also want better ways to communicate with children. One of them felt that signposting is not really child-friendly.

Recommendations & Responses from Evelina Hospital

Recommendation 1

Bigger waiting room - The clinic is visited by up to a hundred patients a day. During busy times, there is not enough space for people to wait. A bigger waiting room would provide not only physical space but would also make patients and relatives less anxious.

Response:

We recognise this waiting space is not ideal for our young people with long term conditions. We plan to investigate the feasibility of using a dedicated space within Penguin zone for our teenagers to use.

Recommendation 2

More age-appropriate activities for older children and parents - It was noticed that the toys and games in the waiting room are for young children. Young people and parents would benefit from age-appropriate tasks/activities, or having some options to choose from.

Response

Our Transition specialist nurse will be surveying our young people with transplants about what they would like to see in our clinic, with regard to resources and environment.

Our multi-professional team will be reviewing what resources are available for our older young people and will ensure there is something available for them to do when waiting. Currently when waiting for blood results our young people have the choice to go to the Evelina London school (during term time), use the internet facility at our KIC centre or use the table tennis table in the Atrium.

Recommendation 3

Shorter waiting times - The waiting time to get the test results could be shorter. This will also hopefully make patients and their relatives less anxious and make better use of their time, e.g. having conversations with the doctors.

Response

We appreciate there are waiting times in our transplant service, however what we offer here is unique in the country. Having today's blood results available when you see the doctor or ANP means when you leave our facility you won't get called back later that day or the next day. This waiting time means clinical decisions are made quickly and treatment started promptly when required.

We feel not having to take an additional day off school/college or work is more beneficial. However, to try to reduce anxiety of long periods in clinical area and to address some of the space constraints highlighted above, we are investigating the option of implementing a buzzer call system which will allow families to leave the immediate area and access coffee shop, school etc. and only return to clinical area when results are back and they are due to see a clinician.

Recommendation 4

Better and bigger signs - It was difficult to navigate through the corridors from ground floor to reach the clinic. Clear signs would help. Also, symbol or drawings, and signs in different languages can be used to benefit those with communication problems.

Response

We are grateful for this feedback from the team as it was not an issue we were aware of. We will discuss opportunities to improve this with our Trust way finding team.

Recommendation 5

Greater emphasis on transition support, including use of language/terms - Instead of using transition, it can be explored if 'transfer' or 'moving to', or 'help with independence' can be used instead. The concepts and the process should also be explained well so that young people and their relatives can understand what the term means and can relate it with the support they are receiving.

Response

We appreciate this feedback. We agree that clear language and discussion with young people at the appropriate time is crucial to successful move to independent management and adult services. This is an area that we have received strong positive feedback on from our patients but will continue to develop this process in conjunction with our patients, families and adult colleagues

We are waiting for vending machines to arrive in the Emergency Department that will supply healthy snacks and drinks.

Conclusion

Four areas have been identified to be of value to patients and relatives such as the care the patients receive, communication and engagement, physical environment, and preparation for transition to adult ward.

First, patients and relatives found that the quality of care is excellent. They also appreciate their access to a wide range of specialist covering a range of medical and social needs. Relatives are happy and could not find fault on the level and quality of care to the young person.

Second, all respondents agreed that feel listened to and are being involved in decisions about their care. They said that staff make it easy for them to understand the treatment by using words that they can understand. They also appreciate that they are being engaged and listened to about their care.

Third, the waiting area is spacious and clean but tends to be crowded at peak times. The young people felt that there is also no separate space for them. The entertainment materials such as board games and toys are suitable to young children. The clinic is also difficult to find for newcomers and the labels are written only in English and not accessible to relatives whose first language is not English.

Last, there is a robust transition process, information, and support available to young people moving from the unit to the adult kidney service. However, this did not resonate in the responses of young people. This can be attributed to the word 'transition' and how the support already being given to them is communicated as being part of the transition process.

Acknowledgement

Healthwatch Lambeth would like to express sincere thanks to the four young people who took part as interviewers and observers. They have shown professionalism and diligence and have contributed their insights to this piece of work.

Thanks to:

Bradley Townsend
Chidimma Nwankwo Soriano
Jaziah Williamson
Naomi Kolawole

Thank you to the schools of those young people:

Dunraven Sixth Form
South Wimbledon High School
ST. Gabriel School

We thank the four staff of Guys and St Thomas Trust/Evelina London for the cooperation and their openness and genuine intention to engage young people in order to improve services.

Thanks to:

Guy's and St Thomas' Hospital Trust staff, namely:

Arran Wheatley
CNS Paediatric Renal Transition

Fatimah Vali
Patient and Public Engagement Specialist

Grainne Walsh
Paediatric Advanced Nurse Practitioner - Renal

Vanda Fairchild
Young Adult Kidney Coordinator - Renal

Healthwatch Lambeth

336 Brixton Road
London, SW9 7AA

Tel 020 7274 8522

Text 07545 211 283

info@healthwatchlambeth.org.uk

www.healthwatchlambeth.org.uk/enterandview

Registered charity no: 1153444

Registered company in England and Wales no: 8430436

