



**Healthwatch Liverpool Enter and View Report
Alder Hey Children's NHS Foundation Trust
Wednesday 26th November 2014**

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Section A

Introduction

General parameters of a Healthwatch Liverpool Enter and View.

Healthwatch Enter and View visits are not designed to be systematic inspections of a health or social care services. Such inspections are carried out by the Care Quality Commission and relevant service commissioners. The Care Quality Commission has the role of assessing and informing the public regarding the general standards of care provided by health and social care services.

Healthwatch conducts Enter and View visits in order to observe a service in action and where practicable, to hear the voices of patients. At best, such Enter and View visits can only offer a strictly time limited snapshot of a service. Healthwatch Enter and View representatives are not health professionals, and so undertake these Enter and View visits from the perspective of a lay-person.

Date and Time of Visit:

Wednesday 26th November 2014 10:30am - 12:30pm

The above were the official period during which Healthwatch exercised its Enter and View powers the was extended to approximately 2:30 pm with the full cooperation of the Trust in order that the Enter and View Team could listen to hear more feedback from staff.

Brief outline of the service

Every year Alder Hey cares for over 270,000 children, young people and their families and it leads research into children's medicines, infection, inflammation and oncology. Next year Alder Hey will open a purpose built hospital in the park next door to its current site.

Alder Hey treats everything from common illnesses to highly complex and specialist conditions from our main hospital site in Liverpool and across community sites and clinics throughout the North West as far as Anglesey.

Alder Hey is...

- A Centre of Excellence for cancer, as well as spinal, heart and brain conditions
- A Department of Health Centre for Head and Face Surgery
- A Centre of Excellence for Muscular Dystrophy and the first UK Centre of Excellence for Childhood Lupus
- One of four national centres for childhood epilepsy surgery, a joint service with the Royal Manchester Children's Hospital
- A designated Children's Major Trauma Centre
- They have Europe's only intra-operative 3-T MRI scanner which is a pioneering technology for neurosurgery, reducing repeat operations in 90% of cases

The visit was arranged with

Hannah Ainsworth,
Equality and Diversity Manager
Alder Hey Children's NHSFT

The reason for the Enter and View Visit

The Enter and View visit was part of the Healthwatch Liverpool activities of:

- identifying whether, and how, local health and social care services could be improved
- identifying whether, and how, local health and social care services ought to be improved
- identifying recommendations to improve the standards of health and social care services
- On this occasion Healthwatch was not following up any specifically indicated quality issues regarding this service, and the main focus was to further familiarize Healthwatch with the operation of this service in order to ensure that Healthwatch Liverpool is well informed when it comes carrying out its prerogative of commenting on the Quality

Accounts and Equality Delivery System submissions that the Trust makes on an annual basis.

The Methodology of the Enter and View Visit

The Enter and View visit was undertaken in accordance with the remit of Healthwatch Liverpool and will assist Healthwatch Liverpool in carrying out its statutory functions under the Health and Social Care Act 2012.

The visit only entered communal areas and facilities. We did not enter any non-communal areas. We spoke to both staff and service users where appropriate.

The visit was conducted by two Authorised individuals from Healthwatch Liverpool, John Roberts and Andrew Lynch. These authorised individuals displayed the requisite identification and provided proof of DBS clearance for the visit.

John Roberts	-	Authorised and trained volunteer
Andrew Jerome Lynch	-	Authorised and trained Development Officer

Healthwatch Liverpool classed this as an announced Enter and View, meaning that the service provider was given notice prior to the Enter and View taking place.

Due to the fact that Healthwatch was not following up any specifically indicated quality issues regarding this service, it was judged that there would have been no advantage by conducting an unannounced visit on this occasion. Announcing the visit also had the advantage of Healthwatch being able to arrange the visit at a time likely to minimize the chances of any disruption to the service that might be caused by our being there.

Section B

The Enter and View Observations

The areas of the service Healthwatch Liverpool authorised visitors visited during the Healthwatch Enter and View were:

- Haematology centre
- K 1 ward
- Cardiac Clinic

Haematology centre

The centre sees 1,300 patients per month and in response to the needs of patients they are going to start a Saturday morning clinics.

The parents use the clinic as a drop in to meet other parents to discuss their children's conditions while there they will see other health professionals. Our

Patient Feedback

Healthwatch visitors met 7 parents who were full of praise for the staff and they commented that the staff were excellent as they went over and above their call of duty. They explained to the Healthwatch visitors that were able to ring them and text them any time they needed help with their child.

For young people the cut off age is 16 years old and at this point young people transition into Adult Services and they would expect this if a child needed extra care. The nurses from adult services do come into talk to parents and children regarding their transition to adult services.

Members of the support group are signposted to different services according to their different needs. They felt that GPs and A & E departments and out of hours services did not understand their children's conditions. They had particular problems with other health professionals not understanding the prescribed medication for their child and they had the nurses on speed dial to speak to doctors about their children's conditions. One parent was in A&E for 9 hrs because they did not understand her daughter's condition. Her daughter is a needle phobic but through working with the nurses they have drawn up a contract to say that she cannot be held down for treatment.

Most patients do not live in Liverpool so it's important that the centre develops long term relationships with the parents/carers and were possible support them to assist in people managing their conditions at home.

One person that a Healthwatch visitor spoke to stated that they had been there for a few weeks and nobody had explained to them the diagnosis and they said that if it wasn't for their own search of the internet they wouldn't know anything.

General observations

The centre was clean but looking a little tired but there has been a concerted effort to brighten it up.

A meeting is to be held in December when the Trust will meet with patients to consult them about the move to the new premises.

K 1 ward

This is a day surgery ward where planned surgery is carried out. 19 different services are offered. They have an ASD pathway to help children with autism. They have reviewed post op care regarding children who have other special needs and do not fit the post op discharge criteria as set by the anaesthetists. They have a Wide Awake Service which was first used for autistic children. This is now used for all children where the team have decided that a child might find it too frightening to wait on the ward pre-operation. Medical staff will make all the arrangements before the child's operation so that the child can go directly from the car park to theatre for treatment. The nurse's come in early to meet the child at the entrance of the car park and they are taken to theatre. The anaesthetist will at the time when considered needed let more than one parent/carer (s) into the anaesthetic room for the child/young person's support and to keep the situation as calm as possible. Their stay on the ward depends on their recovery but some children are allowed home directly from the recovery room. They have a wide range of different information leaflets specifically designed and user friendly for children.

Fabio devices are used to gather the children's experience of the service. Originally the ward used to do an audit of families the next day by phone to get their views of the service but some families felt they did not need or did

not use it. Therefore, they now use an answer machine where they check if any parents have any issues. On the wards they use stickers which have a clock on them. This shows the time the children's medication is due as some families find understanding when to give medication difficult particularly if English is not their first language or they have low literacy levels. They have picture books which are simple in design which explain the whole day. These can be used for children who do not speak English to show them what will happen to them on their arrival day.

Cardiac Clinic

Paediatric Cardiac Nurse Specialist team

The team consists of 6 nurses. They have a diverse role and are able to support all patients from antenatal diagnosis to discharge and onto adult services.

They meet newly diagnosed patients in the cardiac clinics; this may be abnormal heart rhythms to complex heart disease, the team are available to support parents in any of the 16 peripheral cardiac clinics in the region. They have strong links with Royal Manchester Children's Hospital as part of the cardiac network.

They manage several clinics:

Preparation for cardiac surgery

Surgical Pre-assessment clinic identifies any social and psychological issues that need addressing prior to admission, clinical investigations and preparation and information is given at this time. Any clinical disorders and referral's to dentist are made if needed.

Consent and further clinical investigations are done at the surgical pre-admission clinic.

Anticoagulation Service

A nurse led service; several prestigious national awards have been given to the team, including one member gaining a Life Time Achievers Award in 2012.

The programme involves managing patients who have either had cardiac surgery or medical issues that require warfarin an anticoagulant drug. Most of the patients self-test at home on machines and the team manage them via a phone call greatly reducing the need to attend clinics for blood sampling.

Antenatal Clinic

A nurse led clinic held on Wednesday mornings, this support service is for parents who have been told their child has congenital heart disease. The parents are given the opportunity to attend Alder Hey Cardiac unit at any stage from 20 weeks to 32 weeks. The parents will have been previously at the Liverpool Women's Hospital or St Mary's In Manchester. The family can visit the ward and ICU, the facilities we have and meet staff, seeing the environment their child will be in greatly helps alleviating some fears they have

Telephone Help Line

This is managed daily by a member of the team, a support and advice service from 8am -5pm. Calls come from parents/carers, community teams, G.P's, schools, wards and other cardiac centres

Cardiac Feeding Clinic

A unique service, for the past 13 years, the only dedicated cardiac feeding team nationally. This includes a Gastroenterologist, Speech and Language member a dietician and cardiac nurse specialist who facilitate the service. The clinic is held on a Wednesday in 01 clinic, a cardiac Consultant is available on the day. This reduces the amount of appointments a parent will need to attend and enables an agreed approach across the specialisms. The patient then has reduced hospital visits. The team also assesses children from the community and regional pediatric centers.

Section C

Conclusions and recommendations

Alder Hey has come on leaps and bounds over this year and has made every effort in placing the patient and their carer/guardian at the centre of service provision.

Although the decoration and environment looked tired and in need of brightening up, Healthwatch recognises that plans are ongoing in terms of moving patient/services to the new build and that investment into the current building is not cost effective, however Healthwatch Liverpool make the following comments and recommendations pertaining to the visit and the views of patients the Healthwatch visitors spoke to: -

1. Healthwatch was pleased to note that the Haematology centre will now open on a Saturday morning to meet the needs of its patients
2. That staff are developing good communication, trust and respect of their patients through providing open access for carers/guardians/young people via phone or text so that if they have any concerns that can be dealt with. This is welcomed as it contributes to managing their own conditions at home
3. Improve communications across the pathways with other professionals e.g. GP's and A & E so as to ensure that information about the patient, their condition and medication instructions are clear.
4. Make checks so as to ensure that the patient/carers/guardian understands their condition and diagnosis
5. Healthwatch were impressed by the use of a wide and diverse range of child friendly information and communication aids and that patients experience is sought and recorded
6. Healthwatch notes and welcomes the award to Alder Hey for the helpline
7. That consultation and involvement continues with patients, carers and guardians in terms of the plans for the new build

Healthwatch Liverpool Scrutiny

151 Dale St

Liverpool

L2 2AH

***Main Number: 0151 227 5177 on prompt add extension number 3255
for direct contact***

Fax: 0151 237 3998

Textphone: 0151 237 3999

Group email healthwatchliverpool@lcvs.org.uk

Website www.healthwatchliverpool.co.uk

Section D

**Responses Alder Hey Children's NHS Foundation Trust to the
Healthwatch Liverpool Enter and View Report
Alder Hey Children's NHS Foundation Trust
Wednesday 26th November 2014**

Received by Healthwatch Liverpool on Tuesday 27th January 2015

Response 1

(The quote that this response refers to is in the Patient Feedback section, the final paragraph of page 5 of the report).

'Members of the support group are signposted to different services according to their different needs. They felt that GPs and A & E departments and out of hours services did not understand their children's conditions. They had particular problems with other health professionals not understanding the prescribed medication for their child and they had the nurses on speed dial to speak to doctors about their children's conditions. One parent was in A&E for 9 hrs because they did not understand her daughter's condition. Her daughter is a needle phobic but through working with the nurses they have drawn up a contract to say that she cannot be held down for treatment.'

Response: In relation to this patient, this isolated incident has now been resolved and as mentioned in the report, steps taken to meet this child's needs.

During out of hours when the clinic is not operating, parents frequently call nurse specialists to request that they contact A&E to provide some advice ahead of arrival about their children's condition. The nurse specialists will do this, whenever possible, in goodwill. The clinic also operates a 24 hour, out of hours, on-call service of haematology consultants if health professionals need advice.

There are also plans to improve the out of hour's service for haematology patients to avoid prolonged stay in A&E in the new hospital. Patients will be directed from A&E to Ward 3B where there will be a smaller group of nurses. In addition, for short stay admissions, there will be an emergency admissions unit.

The haematology clinic always used the LIFE (Liverpool Information for Emergency) service when it was in operation around 2010 which meant that a haemophilia/ non-malignant haematology patient would be flagged up on the meditech system on arrival to the hospital. This was particularly beneficial in A&E, when an arriving family could often in distress forget their child's treatment regime as it meant an up to date record of treatment doses and recent investigations were immediately available to view online. Funding ended for this enterprise. However the new computer systems available in the new CHP should allow easier access to vital information. One of the nurse specialists will investigate this.

Response 2

(The quote that this response refers to is in the Patient Feedback section, the second paragraph of page 6 of the report).

‘One person a Healthwatch visitor spoke to stated that they had been there for a few weeks and nobody had explained to them the diagnosis and they said that if it wasn't for their own search of the internet they wouldn't know anything.’

Response: There are many types of blood disorder some of which are not capable of a clear diagnosis but can have similarities with more identifiable blood disorders. Investigations can take time and are not always straightforward. However, steps will be taken by nurse specialists to ensure that the communication process includes a provision for ensuring that parents have fully understood the information they have been given in relation to their child's condition and diagnosis at appointments.