

Recommendations

1. Improve **communication** - between health professionals and patients/carers and between healthcare departments. This must be made more effective at all levels and by all healthcare professionals.
2. Build in effective ways of **understanding patients' and carers' experiences** - this is fundamental to how the Trust can continuously monitor and improve quality.
3. Maintain support and engagement for existing **cancer support groups**, and facilitate the formation of new groups for cancer types not already represented.
4. Provide **formal education and training opportunities in ethics for staff** at the Trust and elsewhere in the Colchester area. This will help ensure that all patients are treated with dignity and respect, that there is shared decision-making and that patients are listened to.

Conclusion

The aim of the study was to explore patient and carer experiences of cancer journeys and it was not designed to be a comprehensive assessment of treatment and care at the Trust. The way people feel about their experience of cancer care influences the confidence and trust they have in the wider NHS and also contributes to their overall physical health and emotional wellbeing. Overall, Healthwatch Essex recommends that collecting and learning from patient experience across the cancer pathways at CHUFT and all NHS organisations should form an integral part of their practice and one that is fundamental to improving quality of care. We encourage CHUFT to develop best practice in this area.

Next steps

We are considering carrying out further qualitative research in the next 12 months to gain insight into the lived experience of doctors, nurses and other healthcare professionals involved in the delivery of cancer care in Colchester. We believe that the experiences and views of all those involved in providing and receiving care and treatment need to be heard if improvements are to be made and sustained in the future.

We would like to thank all the patients and carers who took part in this study.

The full report is available at:
www.healthwatchesessex.org.uk

Contact us

-  www.healthwatchesessex.org.uk
-  @HWEssex
-  enquiries@healthwatchesessex.org.uk
-  01376 572829
-  RCCE House, Threshelfords Business Park, Inworth Road, Feering, Essex CO5 9SE

Cancer services in Colchester: a study of patient and carer experience

Background

Healthwatch Essex carried out this study to provide evidence of patient and carer 'lived experience' of cancer care and treatment in Colchester. This was in response to a report by the Care Quality Commission in November 2013 which identified a number of serious problems with cancer services at Colchester Hospital University NHS Foundation Trust (CHUFT).

As an independent organisation, with a legal responsibility to gather information on patient and service user experience of health and social care in Essex, Healthwatch Essex was well placed to carry out this important research.

The importance of patient and carer experience

Along with clinical efficacy and patient safety, **patient experience** is one of the three cornerstones that make up quality of care in the NHS. Yet detailed accounts of how people experience their overall cancer journey are often overlooked in the NHS, and it has the power to remain **vivid in people's recollections long after the event**. It was therefore crucial to investigate this aspect of care at the Trust.

What did we do?

We asked patients and carers who had experienced cancer services at Colchester General Hospital and Essex County Hospital **in the last 3 years** to share their story with us. By collecting in-depth narrative accounts, we were able to build a detailed picture of people's cancer experiences.

We collected people's experiences through:



a survey of
over 170 patients
and carers



focus groups held through
local cancer patient groups -
around 30 people took part



in-depth one-to-one
interviews with
16 patients and carers

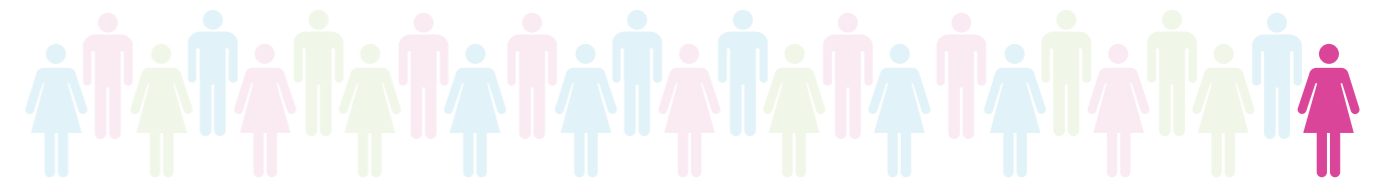
In total, over **200 people** took part in the study. Around two thirds were patients and one third were carers.

What did we ask?

We asked people about how they experienced their **treatment** (surgery, chemotherapy, radiotherapy etc.), and also their care (feeling cared for and supported). We also asked whether they felt their **views/experiences were listened to** by doctors, nurses and others involved in their care and whether they had fed back comments or complaints more formally.

What did we find?

Overall, we found a mixed picture of patients' and carers' experiences. A large proportion of participants had both praise and criticism for aspects of their treatment and care, regardless of whether they were generally satisfied or dissatisfied. **Several key themes were identified.**



Patients' and carers' needs, values and preferences

- Almost all patients were extremely complimentary about the quality of care provided by **Cancer Nurse Specialists**. In particular, they valued the **empathy and support** these nurses provided, and the **extra practical information** they were able to share.
- In addition to people wanting to be treated as individuals, they also had an overwhelming wish to be treated with **care and dignity**. They also wanted health professionals to appreciate that patients often feel vulnerable and need to be **reassured** throughout their cancer journey. Unfortunately, there were many cases where the service did not meet these needs.
- Participants also highlighted their desire to be **kept well informed** about how their treatment was going. Again, this did not happen universally. People who felt they were not being kept updated were less satisfied with their treatment.
- **Choice and control** were also highlighted as important issues. Levels of satisfaction were higher when patients/carers had been involved in decision-making.

“I need to feel like I've got some sort of input or control into what is happening with the treatment, and they have always given me that, which is something that I'm grateful for, because it made me feel like I had a choice.”

Patient with gynaecological cancer

- Many people felt care at the Essex County Hospital was of higher quality than at Colchester General Hospital. Overall, people felt care here was more patient-centred and less time-pressured. The **Mary Barron** suite received an exceptionally high level of praise across the research.
- **Cancer support groups** were regarded as a vital lifeline to many patients.



Communication

- Communication was a key issue. Participants stressed that **clear good quality information, personalised to the individual**, was a key factor contributing to high satisfaction levels.
- The **manner and clarity** in which a cancer diagnosis was given to the patient was considered really important. At the core of many complaints was the feeling that bad news was delivered insensitively, without compassion, and at worst in the middle of a ward, without any privacy. A general complaint was that consultants could deliver diagnoses in an abrupt “mechanical” way that lacked empathy, and that this affects their subsequent cancer journey.

“If you start a journey off badly, it stays with you.”

Patient with gastrointestinal cancer

“We were told the diagnosis with the doctor standing, mumbling and fiddling with notes.”

Carer of sarcoma cancer patient

- **Poor communication** between hospital staff members, and between the hospital and other health organisations such as GPs, was also experienced as a source of frustration by patients and carers.

Quality of care

- Although around two thirds of people reported that they were satisfied overall with the quality of care given, some of these, and others who were not satisfied overall, reported experiences of poor care and a **neglect of basic needs**. For example:
 - Clinical staff did not always listen to patients' and carers' concerns and took a long time to respond to patient requests;
 - Nursing staff said they would be back shortly then didn't return;
 - Patients were often left to tend to their own washing, feeding and toilet needs even when it was apparent that they were unable to do so;
 - Buzzer response times were very slow (or buzzers were not being responded to at all);
 - Many people felt that protocol, process and paperwork appeared to take precedence over basic patient care;
 - There was a perception that poor care was linked to understaffing.
- People repeatedly reported low satisfaction with the quality of treatment and care people received at busy times such as **weekends and/or holiday times**.
- Some people also reported that their **discharge from hospital was rushed** and that once they were technically discharged they were left to 'fend for themselves', when what they really needed was continued support.
- End-of-life care was sometimes not well managed and the **administration of pain relief** at Colchester General Hospital was not always considered to be adequate for some patients who were critically ill.

Appointments and administration

- A recurring complaint was the need to **chase test results and/or follow up appointments**.
- Another frequently-raised issue was appointments being **cancelled and rescheduled** with the ensuing sense of anxiety, frustration and disappointment this causes patients and carers.
- Several people complained about **mix-ups and misinformation**, when people were sent the wrong appointments or not notified correctly of their appointment times.
- A number of patients and carers were dissatisfied with the **length of appointment times**. People felt there was not enough time to discuss questions and concerns, only to deal with immediate matters, and felt time-pressured. People whose appointments were less hurried were more satisfied.

Patient/carers feedback

- Patients and carers felt their views and concerns **were not always being listened to**.
- A number who had cause to complain or provide critical feedback did not do so because they felt **afraid, vulnerable or had lost trust in the system** and felt that complaints would not be heard and acted upon.
- The motivation for many patients to participate in our study was not for compensation, rather for a sense of **closure and improvement to the service**.

“I don't want anything out of this. I just want things to improve for others.”

Carer of deceased pancreatic cancer patient