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## EXPLORING THE IMPACT OF THE BUILT ENVIRONMENT

### The Futures Company Report for Teenage Cancer Trust

January 2010



HELPING YOUNG PEOPLE  
FIGHT CANCER



# Introduction

The aim of this report is to provide an account of a UK-wide service evaluation study that was carried out on behalf of Teenage Cancer Trust. Teenage Cancer Trust is a charity that exists with the aim of providing teenagers and young people with the appropriate environment and support to deal with their cancer diagnosis, treatment and recovery in the best possible way. To this end, they fund and facilitate the construction of specialist units that are built with teenagers and young people in mind. The charity aims to build enough units to enable every young person with cancer to have access to the specialist care and support they provide.

The study took place between May and November 2009 and was carried out by The Futures Company. The Futures Company is a strategic insight and futures consultancy with a wealth of experience in understanding social change and using this knowledge to help clients with their strategic planning.

The Futures Company works with clients across government, including in education and health, with a particular focus on public service transformation.

The aim of this study was to provide qualitative evidence of the impact that Teenage Cancer Trust units have on the experience of patients, their friends and family and the staff who work on the units.

Whilst the work was commissioned by Teenage Cancer Trust and their sponsors, The Futures Company acted independently and without influence. The study does not make any claims with regards to measurable medical outcomes, which fall outside the scope of the study.

The specific objectives of the study were as follows:

## **Primary Objective:**

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What is the impact of the architecture and design of these units on the young people being treated, as well as on their family and friends?

## **Secondary Objectives:**

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What are the particular features in terms of infrastructure, design, facilities or equipment which seem to make the biggest difference to young people and why?

What is the impact of the environment on the medical and hospital staff who are caring for these young people?

While the study was focused on the overall impact of the built environment on patients in general, it was also evident that different segments of the patient sample would have varying needs. For instance, younger patients and their parents are likely to prioritise facilities to stay overnight regularly, but an older patient might have more need for internet access or for flexible visiting hours for friends to visit later in the evening.

Where possible this report details these differences, whilst at the same time acknowledging that the sample sizes at this level of detail were relatively small.

# Approach

To help explore these issues, a broad selection of people with experience on both the Teenage Cancer Trust units, more standard units, and some with experiences of both, were interviewed.

These included current and former patients, friends and family of patients, staff on Teenage Cancer Trust units and also parents of young people who had died as a result of cancer. Care was taken to ensure that the sample covered a range of patient ages, cancer and treatment types and different lengths of stay in hospital.

In total, 15 patients, 6 parents or partners of patients and 6 health professionals with a broad range of experience across the units were interviewed. With many of the patients and their parents and partners having experienced both Teenage Cancer Trust units and standard wards, there were a total of 31 experiences.

An initial series of interviews with various stakeholders was also carried out. These included in depth interviews with senior professionals from the health care, architecture and design communities. In addition to this, significant amounts of desk research were also carried out, including previously conducted research (Denver 2006). The team also drew on the database of patient generated videos on [www.jimmyteens.tv](http://www.jimmyteens.tv). This helped to add a further initial level of understanding of the context of patients' lives.

Each of the respondents was interviewed for approximately one hour, covering a range of different topics. Due to the sensitive nature of the subject matter, not all respondents were comfortable discussing all areas of interest to the study. Care was therefore taken to ensure that

respondents were given the freedom to decide which areas they wished to focus on.

This meant a flexible approach was used within the interviews, (drawing on a discussion guide, as set out in Appendix I). Hospital locations included: Sheffield, Northampton, Birmingham, London, Manchester and Cardiff.

The main areas covered were:

**An understanding of the context** – Exploring the respondent's broad experience in terms of the type of cancer and treatment they had, which hospitals and wards they were treated on, what their initial expectations of the wards were and so on.

**An understanding of their life** – Exploring their particular personal areas of interest and activities that they enjoyed, in order to understand the broader context of their lives and the ways the diagnosis of cancer might have impacted on them. This included an exploration of the different environments in which they spend time during normal life (including home) and any differences in the way these places look and feel, understanding what it is about those places that make them more or less enjoyable to spend time in, and why different things were desirable at different times etc.

	Age		Unit Type		Treatment Type	
Patients	12-16	17-24	Standard	TCT	Long Term	Short Term
Parent / Partner	2	4	3	5	4	2
Total		21		31		21

## An in-depth exploration of their time on the units or wards

What they looked like, how they felt; how they compared to places that they usually spend time in and what difference this made; what non-medical equipment they had access to and how important this was; how they spent their time and how else they may have wanted to; how much control they had over various aspects of their experience on the units; what they would have liked to change and so on.

These areas were explored with the aim of helping to answer the following questions:

### Understanding the patient journey and the impact of the treatment environment:

- > What are the drivers of patient experience within the treatment centres?
- > What needs are being met and which are not within Teenage Cancer Trust and other centres?
- > What features of the environment have the biggest impact on young patients and why?
- > What trade-offs would young people want to make and what are their priorities?

Similar areas were explored with the friends and family members of patients who were interviewed. In addition, these groups were also asked about their expectations of the wards and what facilities there were to cater for them; what facilities they would have liked to have been available and how well they thought the units helped them to support the patient.

These were explored to help answer the following questions:

### Understanding the needs and experiences of friends and family:

- > What is the impact on friends and family of the treatment environment?
- > What are the primary needs that friends and family expect units to meet?
- > What features of the environment have the biggest affect on friends and family and why?
- > What additional features would friends and family like to see?

Interviews with staff were carried out to explore the ways in which the environment impacts on how they can carry out their job, and the different aspects that could be changed or improved. These areas were explored to answer the following questions:

### Understanding the impact of the environment on medical and hospital staff:

- > What are the strengths and limitations of standard wards and Teenage Cancer Trust units in terms of clinical care?
- > What aspects of the treatment environment do staff particularly value?
- > What features of the environment in the Teenage Cancer Trust units do medical staff feel have the strongest impact on young patients?
- > Having detailed the approach that was used in this study, the following section provides an executive summary of the findings and then explores the findings in detail.

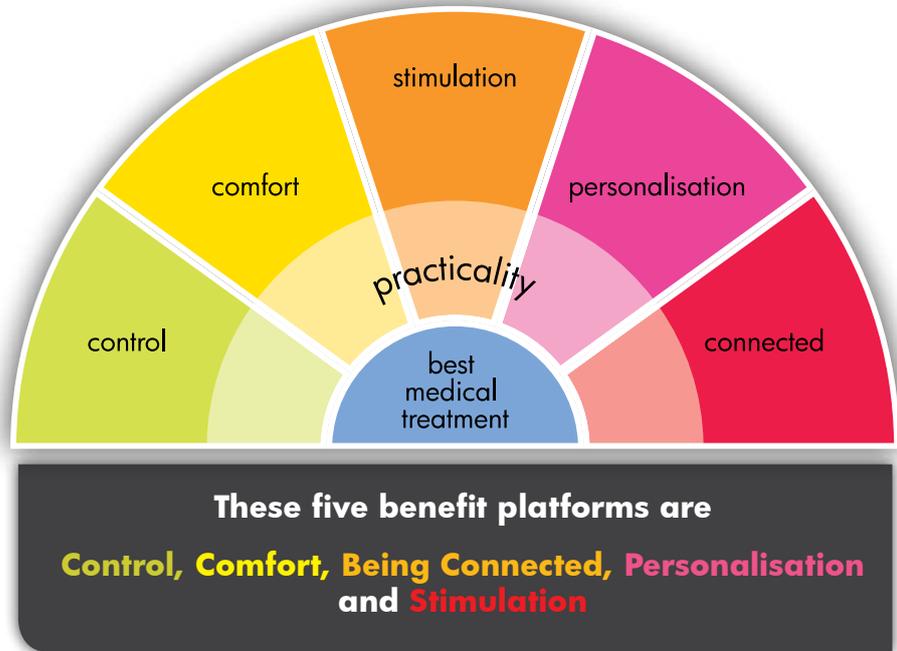
# Findings

The primary output of this study was the recognition of five key benefit platforms that Teenage Cancer Trust units provide across the three user groups:

- > Patients
- > Friends and family
- > Staff

Each of these is introduced and discussed in detail below. While the value of each of these platforms may vary significantly for each patient, they are all important and they often overlap and reinforce each other. For instance, computer equipment meets both stimulation and connectivity needs. Therefore it is neither possible nor desirable to place these into a hierarchy. Instead they should be seen as segments of an arch whereby each segment reinforces the others and the removal of any individual section leads to a considerable weakening of the overall effect.

The importance of accounting for the impact on the three user groups detailed above, is also a significant consideration in this study.



As per the objectives, this study was primarily concerned with exploring the impact of the built environment on patients. However, it was clearly apparent from the findings that both staff and patients' friends and family play a vital role in the overall experience of young people on the units. For this reason, it was also important to understand the impact which the built environment can have on these groups.

These three groups all interact with the wards in different ways and while the primary beneficiaries are the patients, improving the environment for their family and friends, as well as the staff who work on the ward, will also be to their advantage

## Patients

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The units can be a permanent home for months on end, somewhere that they visit briefly, or somewhere that they visit regularly for short periods, over months or years so they must cater to many different needs.

The benefit platforms help to maintain a sense of 'normality' for all those involved. For some this means maintaining normality as far as possible as it was prior to diagnosis and treatment; for others it means adapting to, and maintaining their new normality. Many young cancer patients recover and move on with their lives. For these young people, maintaining normality in this context can be understood as doing as much as possible to 'ensure that cancer is a comma' (in the words of one of our health professional interviewees), rather than a full stop, in patients' lives, so that they are able to resume normal life again as effectively as possible.

For some, the changes that a cancer diagnosis and treatment entail mean that normality will be impossible to maintain. Nevertheless, it is important that this new normality should carry forward the maximum of

links and contacts from their old lives and be maintained for as long as possible.

### Several reasons were suggested for this:

- > Encouraging patients to carry on with their lives gives them a sense of being able to 'come out the other side', maintaining relationships and pursuing life goals and as well as educational achievements, where feasible.
- > It stops patients defining themselves by their illness and can help combat feelings of depression and isolation that can be common on teenage and young persons' units.
- > Particularly for long term patients, it makes it easier to adjust back to living outside of the hospital environment. In what is a very dependent environment, it is important to help maintain a sense of independence.
- > For those patients who do not recover, and their families and friends, it supports coping mechanisms and enables family and friendship units to be maintained as much as possible for as long as possible.



# Staff

The staff on the units encompasses nurses, consultants, youth support coordinators, cleaners, housekeeping, alternative medicine practitioners and other allied health professionals. For these individuals the units are their daily working environment and as such, its design can have an impact on the way they are able to perform in their roles.

Designing the optimum working environment facilitates staff in better meeting the needs of the patients, and their friends and families, on emotional as well as physical levels.

There are three main ways the built environment can have an effect on the staff:

- 1 Ensuring that functional spaces such as the nurses' station and sluice rooms are in the best possible location within the ward to allow them to be used as appropriate. For instance, the nurses' station needs to provide good visibility of the bay areas whilst having an element of privacy to allow discussion of sensitive issues.
- 2 Providing sufficient provision for staff to have their own space. This means that the environment supports, rather than inhibits their ability to do their jobs.
- 3 Working in a brighter, well maintained environment is important to help create an up-beat atmosphere, given the inherent difficulties of working on a teenage and young person cancer ward.



# Friends and family

Family and friends can cover a wide network. Parents are likely to be the most regular visitors, often staying overnight, but the needs of siblings and the wider family, as well as friends and sometimes partners should also be considered. As stated above, one of the aims of the units is to maintain normality.

For most youngsters a large part of normal life is spent socialising with their peers and living with their family. It is therefore important that the units facilitate the continuation of both of these as much as possible. Both friends and family members can be crucial in helping patients to come to terms with their illness and also passing their time in the units in a more enjoyable way.

Making the units more accommodating for these groups will make it easier for them to support the patient that they are visiting. Where these facilities are not in place, this can cause considerable problems:

"THERE WEREN'T ANY FACILITIES FOR PARENTS TO VISIT. WE EVEN HAD TO ASK SOMEONE TO GO AND FIND US SOME CHAIRS SO WE COULD SIT BY HIS BED WHEN HE WAS WAITING TO GO INTO SURGERY."

Parent of patient on standard ward

Parents of younger patients in particular may want to stay overnight on the unit on a regular basis, as well as needing adequate facilities to spend time there during the day. This is all the more likely if they are not based locally and have travelled long distances, as is often the case.

In addition, hospitals are often unfamiliar and can be threatening for many young people and teenagers – more appropriate design can make friends and siblings feel more comfortable and make them more likely to visit.

The environment of the units that their loved ones are spending time can be a significant concern for friends and family. If they know that their child, partner, or friend is going to be as comfortable as possible at times when they can't be there, then this can be very reassuring:

"JUST SEEING ALL THE KIT THAT THEY HAD IN THERE MADE IT MUCH EASIER FOR ME TO ACCEPT THAT HE WOULD BE OK EVEN IF I WASN'T THERE ALL THE TIME."

Wife of patient on a Teenage Cancer Trust unit



# Control

Control is an important benefit for young people because of the life context. Young people on the units are likely to be going through a period in their lives where they are just starting to gain control through increased independence. It is a time in their lives where as teenagers they expect and are expected to push boundaries and start to develop and identify themselves through the choices they make. So the implications of having so much control suddenly taken away, due to cancer, are even more significant.

The patients have had little choice with regards to being in hospital, removed from their normal context of life at home, school, work and taking part in social activities and hobbies. This backdrop is likely to be different for each individual but the disruption is the same. This disruption is likely to have a negative impact on any patients who are taken out of the familiarity of their daily lives and forced to adjust to hospital life.

For young people, having to deal with this, just at the point when they may be starting to gain more control over their day-to-day lives, is all the more challenging.

So within this context, control is defined as the ability to make and act out choices about aspects of life that would reasonably be expected to fall within the normal balance of everyday life.

Within the hospital environment this encompasses decisions regarding when to go to bed and when to get up, when to have meals and what to eat and many other small aspects of day to day life.

Factors such as having a choice over the lighting surrounding the bed may sound trivial, but for patients with more serious conditions, and also those approaching the end of life, just being able to control one aspect of the environment through the colour of lights can make a big difference.

Control over each of these aspects may not make a big difference in isolation, but placed together, within the context of having lost so much freedom and choice as a result of being hospitalised, maintaining a sense of control becomes increasingly important.

## Why is Control important?

Control is important within the unit setting for the same reasons that it is important in normal life. Each of the five benefit platforms work together to best recreate a sense of normality, with control playing a significant part in this process.

For friends and family control is also important. Having the ability to visit whenever is desired or possible, rather than being restricted by visiting hours makes it much easier for them to support the patient. It means that normality with regards to socialisation and the family unit can also be more easily maintained.



Families can cook, eat and socialise together and friends can visit at hours appropriate to them -including, in some cases, after having been to the pub. They can play pool, listen to music and play computer games, much as they would outside of the hospital environment. This helps the patient in terms of maintaining their social status and ensures that they look beyond their treatment and don't define themselves by it.

It is also important to note for patients the importance of maintaining a sense of responsibility to minimise any sense of institutionalisation. For many patients they will be at an age where they are starting to take an increasing amount of control over many aspects of their lives, to lose that control, therefore, can be particularly difficult.

*"YOU'RE AN ADULT SO TO SUDDENLY HAVE TO LIVE BY SOMEBODY ELSE'S RULES THAT JUST DON'T HAVE ANY RELATION TO HOW I WAS LIVING BEFORE I WAS DIAGNOSED IS JUST REALLY DIFFICULT."*

Patient on standard ward

If everything is done for them and they have little choice in so many aspects of their lives, then this is likely to have disruptive consequences once they have left the units and have returned to a situation where they do have to resume responsibility for themselves.

### How do Teenage Cancer Trust unit facilitate control?

Teenage Cancer Trust units aim to give patients an appropriate level of control over all aspects of their environment whilst in hospital, as long as their actions are not disruptive to other patients. In the first instance,



the separation of the social spaces and ward spaces helps to minimise disruption. This gives patients the freedom to choose when to go to bed and when to get up.

To further aid this, all the units provide cooking facilities so that patients (and often also their parents) can cook for themselves, rather than having meal times including breakfast dictated by the ward timetables. The provision of cooking facilities and storage space also means that patients have freedom of choice and control, not only over when they eat, but also what they eat.

This can be particularly important again for patients undergoing chemotherapy or treatment for leukaemia who can experience changes to their sense of taste and smell as side effects of the treatment.

As the quotes below demonstrate, food and meal times can be of high importance to the well being of the patients:

"THE WARD WAS RIGHT AT THE TOP OF THE BUILDING AND HOUSEKEEPING JUST WORKED THEIR WAY DOWN; I HAD TO HAVE BREAKFAST AT 6AM."

Patient on standard ward

"I DON'T THINK THAT SHE ATE ANY HOSPITAL FOOD THE ENTIRE TIME SHE WAS THERE - EITHER I COOKED HER SOMETHING OR SHE HAD A CUPBOARD WHERE SHE COULD KEEP FRUIT, CRISPS AND BISCUITS"

Mother of patient on Teenage Cancer Trust unit

Patients are also given the freedom to choose how they pass their time whilst on the units. Computer and television facilities including Wiis, laptops and broadband internet are provided free of charge to enable patients to spend their time in the same way as they would outside of the hospital. In some units there are also facilities for patients to continue their studies with many patients likely to still be in some form of education when they are admitted.

Not only is this important in terms of allowing them to maintain normality whilst on the units, it also means that they won't have fallen behind when they return to the education system once they have left the units.

A relationship was also noted between the severity of the patient's illness and the extent to which control became important – with control increasing in importance, the greater the severity of the illness (for example, for patients facing long-term stays or end of life).

A relationship was also noted between the severity of the patient's illness and the extent to which control became important – with control increasing in importance, the greater the severity of the illness (for example, for patients facing long-term stays or end of life).

To this end, the areas around the beds are also designed with control in mind. Not only might the patient have complete control over the level and type of lighting that they have, there may also be different types of curtains that allow the patient to choose how much privacy they have from the rest of the ward.

Patients can choose to screen everybody out, while still allowing staff sufficient access to maintain best medical practice. In addition, they can use a more transparent curtain that allows some interaction with the ward whilst keeping some sense of privacy.

The provision of white boards and picture frames and hooks also gives patients control over how they decorate their immediate surroundings – much as they might in their own bedrooms at home. This capacity for control over the immediate environment is explored in more detail in the section on Personalisation.

These elements in combination all act to return as much control to the patients as possible to help maintain a sense of normality. For the staff,

providing greater control and independence to patients, in what can otherwise be a very dependent atmosphere, helps to change their role from being a potential 'enforcer' of rules as well as care giver, to being someone who can focus more on supporting and enabling the patients.

The extent to which control is facilitated also extends to the way in which patients are encouraged to engage with the medical treatments. For example, we heard of cases where rather than being forced to take their pills at set times, patients were given an element of control over timings without contravening best medical practice (allowing them to sleep in, for instance).

By allowing this greater level of control, patients are likely to be more positive about their treatments and less likely to reject them.

## Considerations for the Future

Many existing Teenage Cancer Trust units currently meet control needs effectively in the ways set out above. However, there are ways in which this could be improved and other areas where care needs to be taken. And it is important to note that while control is important for patients, it should not be to the detriment of either their own, or other patients' medical care. For example, while the freedom to have visitors at any time and for parents to spend lots of time with their children is important, these benefits should be monitored to ensure that patients don't spend all their time with their parents, or indeed disrupt other patients who are trying to rest by receiving visitors.

An additional aim of the units is to ensure that patients do not start to define themselves by their cancer, or assume that they are 'special' by virtue of their illness.

So giving too much control to patients where it may not be appropriate - for example, letting them get away with behaviours that would not necessarily be tolerated outside the unit - should therefore be avoided.



# Staff

While comfort might not be top of mind for most teenagers and young people in every day life, it becomes increasingly important once they are taken out of their usual environments. Comfort should be understood here on both physical and emotional levels. Physical comfort relates primarily to the furniture and space that the patient and their family and visitors occupy when they are spending time on the units.

This includes both the patients' beds and also any seating in the units. Given the amount of time that both patients and visitors are likely to spend in them, it is essential that this aspect of the environment is considered fully. For patients, the physical comfort of the seating is particularly important given that they are likely to spend the majority of their time on the ward either sitting down in the social areas or receiving treatment in specialised seats.

Emotional comfort relates to the way the ward environment puts patients and their friends and family at ease. Hospitals can feel threatening and uncomfortable places at the best of times, so when a young person or their family is there because of cancer, it is all the more important that this need is addressed. Emotional comfort also means giving patients and their families the opportunity to have some privacy and time away from other people.

This can either be addressed through controlling the immediate environment by lighting or screens, or by providing different physical spaces within the units.

The needs of the staff for whom the units are their day to day working

environment, are also important here. Working in hospitals and cancer wards in particular can be difficult for staff, for obvious reasons. So anything that fosters a more positive working environment will offer immediate benefits to them as well as the patients.

## Why is Comfort important?

Very often, cancer treatments cause patients to suffer high levels of discomfort for prolonged periods of time. For some, this will mean feeling nauseous and weak and being restricted to a bed. Being able to adjust the bed's positioning to be able to watch TV, play computer games or simply communicate more easily with patients or visitors takes on a heightened importance.

For others, more serious treatment can mean loss of limbs or more extended periods confined to beds, often with intravenous drips. Increasing the level of comfort within which patients receive their treatment can make a painful experience more comfortable and can also increase their likely compliance with treatment programs.

For the most unwell or those who have lost limbs, accounting for physical comfort needs is an absolute necessity in allowing them spend their time in the units in the least painful way possible. For those who

" OBVIOUSLY THE MOST IMPORTANT THING IS THAT THEY GET BETTER, BUT JUST BECAUSE YOU'RE GOING THROUGH A HARD TIME, IT DOESN'T MEAN THAT YOU DON'T APPRECIATE THAT A BIT OF THOUGHT HAD BEEN PUT INTO WHAT THE ENVIRONMENT IS LIKE."

Mother of patient, non standard unit

are less well, physical comfort may not be such a necessity, but its importance should still not be underestimated:

The importance of emotional comfort is easy to underestimate. For many young people, hospitals are unfamiliar and threatening places. This means that patients' friends or siblings may find it difficult to visit, which in turn means that the patients are more likely to become isolated from their peers outside of the units. As stated above, one of the functions of the units is to lessen the extent to which patients become institutionalised.

Designing an environment that facilitates continued communication with existing support networks obviously helps to meet this need. This sense of being connected is discussed in more detail below.

## How do Teenage Cancer Trust units facilitate comfort?

Teenage Cancer Trust units are designed and furnished with comfort in mind. The beds are fully adjustable to allow the patient to position themselves in the most comfortable position possible, dependant on both the activity that they are taking part in and the discomfort that they are facing. This can be as simple as raising the end of the bed to allow them to watch TV or to speak more easily to visitors. The chairs in the treatment rooms are also specially designed to make the patients as comfortable as possible while receiving their treatment.

In conjunction with being stimulated, (as discussed below in the section on Stimulation) the TVs and graphics on the walls and ceilings also act to markedly improve the treatment experience for both patients and staff.

One of the most noticeable elements when walking into Teenage Cancer Trust units is the way they look; they are very different from

standard hospital environments. The entrances often have feature lighting or mirrors that immediately signal the differentiation from more standard wards. This was often commented on as being important to the patients, as well as their families, as it helped to put them more at ease when entering an environment in which they knew they might have to spend considerable amounts of time.



*" OBVIOUSLY THE MOST IMPORTANT THING IS THAT THEY GET BETTER, BUT JUST BECAUSE YOU'RE GOING THROUGH A HARD TIME, IT DOESN'T MEAN THAT YOU DON'T APPRECIATE THAT A BIT OF THOUGHT HAD BEEN PUT INTO WHAT THE ENVIRONMENT IS LIKE."*

Mother of patient, non standard unit

# Comfort

The units are designed to look more like a youth social space or young person's bedroom than a typical hospital ward. This aim is achieved through the use of brightly coloured furniture, graphics and prints on the walls. The design of the space around the beds also contributes to an increased emotional comfort.

Where possible, all of the medical equipment is hidden from view in cupboards and under the bed and this demedicalised look helps to minimise the feeling that the patient is actually in a hospital.

This emotional comfort not only improves the patients' time on the units, but also makes it easier and even more enjoyable for their family and friends to visit.

## Considerations for the future

While both the physical and emotional comfort of the units are essential, it is also important to recognise that what is most comforting to young

people, might not always be consistent with 'high end' design. While the designs within the units were universally appealing to those who spent time there, there were occasions where it was felt the design risked being pushed too far away from what young people felt was normal or comfortable. For example, some patients felt that rather than the new, designed sofas, a more comfy 'worn in' sofa to curl up in, might be preferable - more in keeping with what they may be used to at home or in other familiar social spaces.

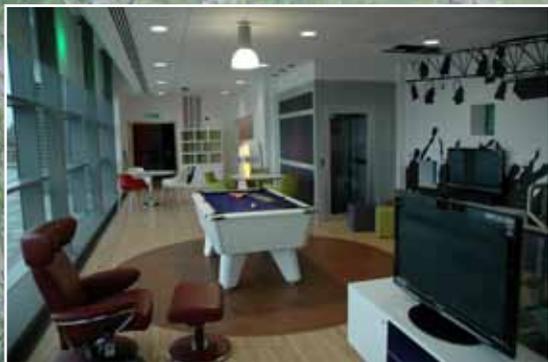
So while the look of all of the furniture is important in terms of increasing emotional comfort, it is important that it is not prioritised at the expense of physical comfort. And small details can have a big impact.

Not only does the furniture need to be as comfortable as possible, it also needs to be positioned in a manner that allows the patients to interact with the other facilities and people as intended.

For example, while having comfortable sofas is important, if they are not positioned in a way that makes it possible to see the TV screen, or if there's nowhere to position the IV drip stand, then considerable value is lost.

Consideration should also be given to all the senses on the wards – not only look and feel. Many patients and their families mentioned the smell on wards - a common issue in hospitals. Patients talked about the unpleasant smell of chemo in urine samples and the fact that during the night many samples could be left in bathrooms for collection by the night staff.

Further comfort benefits could be realised by a focus on minimising any distressing smells which evoke hospitals and cancer treatment, for example: ensuring prompt collection of urine samples and the appropriate location and design of sluice rooms.



# Stimulation

Stimulation can best be understood as the way the units are designed to engage and stimulate both patients and their friends and family, distracting them from the day-to-day routine, reality and discomfort of cancer treatment.

## Why is Stimulation important?

Stimulation, as with the other platforms, is important because it is part of everyday life. Teenagers and young people obviously participate in all sorts of different activities which differ for each individual but often include education and learning as well as socialising and entertainment in a range of forms. In the context of Teenage Cancer Trust units, stimulation can include playing games, watching TV and films, reading, listening to music, arts and craft and so on.

These activities are very important in distracting patients from some of the day-to-day problems associated with cancer treatment. For example, TVs, pictures on the ceilings and/or walls and window blinds in treatment rooms act to minimise the discomfort and unpleasantness of treatment procedures.

Boredom can also be a common problem on cancer units with young patients being forced to spend large periods of time away from their regular support networks. So anything that helps to pass the time can be important in keeping up morale.

## How do Teenage Cancer Trust Units facilitate Stimulation?

Many of the features which facilitate being connected on Teenage Cancer Trust units also provide important stimulation. Broadband enabled computers, jukeboxes, pool tables and musical instruments all contribute to providing stimulation and entertainment to patients. Youth support coordinators also run film or pizza nights and other arts and crafts activities that both encourage patients to engage with each other and also stimulate them.

These are also important as they can provide a sense of structure in what can be an unstructured environment, and give patients something to look forward to.

On a broader level the walls of the units are decorated with different designs, patterns and images that all act to decrease the feeling of being hospitalised. While this contributes to emotional comfort, it also facilitates stimulation.

The pictures of bridges, woodlands, tropical fish and skies all act to engage the imagination and facilitate a sense of escapism that allows patients to remove themselves from the immediate reality of life with cancer.

*"HAVING IMAGES FROM ALL OVER THE WORLD OR JUST OUTSIDE MAKES IT EASIER TO IMAGINE THAT YOU'RE NOT COOPED UP IN A HOSPITAL - IT'S ESCAPISM REALLY AND I THINK THE PATIENTS REALLY DO FIND THAT IT MAKES A DIFFERENCE."*

Teenage Cancer Trust nurse

Large windows and outside space also facilitate stimulation through access to the outside world, weather, time of day and for longer term patients, different seasons.

## Considerations for the Future

Each individual on the unit is likely to have different interests and therefore be stimulated by different things. As with personalisation above, there is the potential for clashes between what a thirteen year old girl would want on the wall and what a 22 year old man might want. Cultural differences are also likely to play a part here.

This can mean that more broadly appealing images should be used, such as woodlands or skies - less likely to be inappropriate for anyone, although not necessarily anyone's first choice.

## Practical Needs

In addition to the five benefits laid out above, and the provision of Best Medical Practice, there is one further critical need that Teenage Cancer Trust units cater to. For all three user groups, it is essential that practical needs are met. Practicality is defined here as benefits which enable the units to run smoothly and to their optimum performance. For instance, the benefit of having free access to TVs and computers is limited if the seating around them is uncomfortable; the benefit of having designs and graphics on the walls of the bathrooms is partially compromised if the same room is also used as a temporary sluice room and smells of urine. As one patient said:

"SOMETIMES I USE THE VISITOR TOILETS BECAUSE THEY DON'T HAVE ALL THE URINE SAMPLE BOTTLES IN THERE - THEY DON'T HAVE THE PICTURES" Patient on Teenage Cancer Trust unit

Each of the different user groups on the units have distinct Practical Needs. For patients it is important to ensure that the equipment is positioned correctly, i.e. seating and furniture that not only looks right but is also comfortable for those who are undergoing or have undergone significant treatment. For example, it's important there should be space for a drip stand next to chairs and sofas.

For the staff on the units it is important that all the facilities are in the right place and that the unit is integrated effectively within the rest of the

hospital. For example, the sluice room should be in the most convenient location; and portering and house-keeping should be considered to allow them to function as they would on any other units or wards in the hospital.

It is obviously important that the design of the units does not hinder Best Medical Practice – consideration needs to be given to ensure that the social spaces are sufficiently clear and laid out in a way that will not represent a risk to patients who may be uncertain on their feet after surgery or who may have drip stands and tubes.

Access also needs to be kept clear at all times for crash carts to be able to move around the units as needed. For parents of patients it is desirable that 'Parent' rooms should allow sight of patient areas so that they can still feel in touch with their children even if they want to give them some space. This allows them to replicate a more normal parent-child relationship whereby they may be sharing the same space, without necessarily being side by side all of the time.

# Personalisation

This is a period in young peoples' lives when they are experimenting with who they are and what they like; in many ways often identifying themselves by their differences. Finding themselves in a situation and environment where they are unable to express these differences can be very challenging, particularly for older patients who are accustomed to being able to modify their environment to suit their tastes. This need for personalisation can be expressed as simply as putting up posters on a wall, choosing what music to listen to or what TV programmes to watch.

In standard hospital cancer units young people can feel as though their identity is compromised as a result of the constrained freedom and control that they have in these respects, and the neutral nature of the spaces with plain walls, curtains and ceilings. Personalisation can also be extended to encompass the way patients are able to engage with their treatment through alternative and holistic therapies.

## Why is Personalisation important?

The ability for patients to take ownership of their space and create a sense of home is important, particularly for those spending long periods of time on the units. This increased sense of home is also likely to contribute to improving emotional comfort. For many patients, cancer treatment can lead to physical changes that dramatically alter the way they look. Hair and weight loss mean that many of the ways in which individuals previously differentiated themselves, are no longer relevant. To be placed in an environment that further challenges this sense of self can be particularly dispiriting for these patients.

For those patients who are more seriously ill, and indeed those who go through end of life on the units, personalisation takes on a markedly increased level of importance. While it may seem insignificant in the context of serious or life ending illness, the ability to maintain control over something as simple as the colour of the lights when all other control has been lost, can offer some comfort.

Indeed it was found that the more ill a patient is, the greater the desire to be able to personalise and take control over any aspects of their life, including significantly the environment.

## How do Units facilitate Personalisation?

Teenage Cancer Trust units offer young people the freedom to recreate their preferred environment as much as possible. There is significant scope to allow patients to modify their immediate environment without having an adverse impact on medical outcomes. Patients are allowed to bring in their own bedding, for example, so that they can have their own duvet from home, rather than hospital sheets.

Patients are encouraged to personalise the space around their beds with shelf space and photograph frames provided to allow them to bring their own lives into the units.

*" JUST BEING ABLE TO HAVE MY OWN DUVET COVER AND A DUVET RATHER THAN SHEETS MADE IT FEEL MORE LIKE MY SPACE."*

Patient on Teenage Cancer Trust unit

Whiteboards are also provided around the bed spaces so that pictures and messages can be written and shared by patients, and their families and friends.

The ability to control the lighting within the patients' immediate environment takes on an increased importance for those who are most ill. Some units allow each patient to have complete control over the colour and brightness of the lighting within their bed space, via a bed side panel.

As discussed in the section on control, patients may be able to cook and prepare their own food at times that suit them. Choosing the extent to which they wish to be engaged with life on the units is also important to patients. While the units aim to be inclusive and encourage interaction between patients, there are also times when young people will want to be by themselves and have a greater sense of privacy.

On Teenage Cancer Trust's unit in Cardiff, the bed spaces on the units are separated by two different types of curtain that allow the patient to decide how much they want to let the outside world in. Heavier curtains mean that more of the unit can be shut out, whilst still maintaining the necessary access for staff. While this is also related to control, it is control with regards to personalising their immediate environment.

By providing these spaces the units allow the young people to personalise the space within which they spend their time, both in a local decorative sense, and also a broader physical sense.



There are also small side rooms and areas where young people can spend time, on their own. And for many patients there are periods where they simply need some time and space to understand and come to terms with what they are going through.

By providing these spaces the units allow the young people to personalise the space within which they spend their time, both in a local decorative sense, and also a broader physical sense.

## Considerations for the future

The importance of allowing young patients to modify their immediate environment becomes clearly apparent when one considers the impact of the absence of this freedom on standard wards.

Patients and parents of patients who had experience of both standard and Teenage Cancer Trust units were quick to express their frustrations about

experiences on wards where they were unable to put up their own posters for example, display get well cards, or watch films of their own choice.

Of course, it is also important to consider the impact that these choices might have on other patients within the bays and to be sensitive and considerate to any cultural or gender issues in order to avoid causing offence.

It may also be possible in the future to allow patients to personalise their space through the use of concertinaed or soundproofed walls. This would also help increase patient control over several aspects of their life on the units.

# Being Connected

A large part of teenagers' and young peoples' lives is related to being connected with both their peers and social groups, and also the interests and activities that connect them.

This will vary largely for each individual but can be about keeping in the loop with a favourite band, football team or TV soap. This also encompasses maintaining communication with existing support networks and contact with activities that help to structure their lives. For many in this age group this will include a continuation of education, whether at primary, secondary or even university levels.

Maintaining and strengthening family and friendship support networks takes on an increased level of importance at what is a very difficult and challenging time for most young cancer patients. For this age group in particular, being permanently connected has moved on to a different level from previous generations.

Advances in technology and the rise of social networking sites such as Facebook and Twitter means that many young people have open communication channels with their peers on a near permanent basis.

However, being connected goes beyond life online and existing friendships and includes encouraging patients to connect with the other young people on the units.

*"I WAS IN THE MIDDLE OF BUYING MY FIRST HOME AND IT WAS REALLY IMPORTANT THAT I COULD SEE MY EMAILS AND KEEP THE PROCESS MOVING FORWARDS."* Patient on Teenage Cancer Trust unit

## Why is being connected important?

Maintaining connections with support networks is important for several reasons:

For younger patients in particular, maintaining a close connection with parents or siblings, at such a difficult time, allows them to draw on familiar support networks when they need them most.

- > Encouraging patients to continue with interests or hobbies allows them to look beyond their illness and be more positive about recovering and returning to a sense of normality.
- > For those who recover and return to the outside world, having remained connected means they are more able to fit back into their previous lifestyle and are less likely to have become 'institutionalised' or defined by their illness.
- > Immuno-suppressed or patients nearing the end of their life may not be able to leave the units for long periods of time, if at all. So for friends and family who are unable to visit, good communication facilities including phones and computers may be the only way of keeping in touch during critical times.
- > Older patients may also be going through other important processes such as buying a house or car, organising a holiday or looking after parents or even children. Being able to continue with these things is important in terms of getting on with day to day life and responsibilities and also setting up something to look forward to once they have recovered.

Being connected means maintaining family relationships as effectively as possible. The parents of patients at the younger end of the spectrum or those who are most ill, are more likely to want to be on the ward with

the young person as much as possible. This can extend to practically living on the units for days or even weeks at a time - particularly where patients have travelled further from home to be on the units. So it's important that facilities within the ward environment can cater to this need.

For some patients being connected also means being able to maintain a connection with the outdoors and outside space. Spending extended periods of time within the units can mean that individuals have little or no contact with the outside world and this can be disorientating in terms of both the time of the day and also the different seasons. Natural light can also be important to patients who can become dispirited by continuous exposure to artificial lighting.

## How do Teenage Cancer Trust Units facilitate being connected?

In terms of communication, obvious elements such as providing free telephone and computer equipment and broadband means that patients can be online as often as they would be in normal life – or even more so given the amount of time that they are likely to be spending on the units.

This allows them to keep up to date with all the things that they are interested in and also communicate with friends over any distance via social networking sites, forums and blogs.

For many young people, keeping in touch with friends all over the country (or even the world) takes place in an online environment and so facilitating this from within the unit means relationships retain a higher degree of normality.

The impact of not having access to communications equipment can be seen with this quote from a wife of a patient on a standard ward:

*" WE SPENT A THOUSAND POUNDS USING PATIENT LINE★ IN ABOUT A MONTH – IT WAS RIDICULOUS BUT I COULDN'T GET THERE FOR WHEN THE VISITING HOURS WERE SO IF I WANTED TO SPEAK TO HIM WHAT ELSE COULD I DO?"*

Wife of patient on standard ward

However, as highlighted above, being connected is not just about the online world, it is also about maintaining connections with existing friends and family and new friends on the unit. An absence of restrictive visiting hours means that patients' friends and family can visit whenever they like and for as long as they like. This is very different to the norm in more standard wards, where there are specific visiting hours and limited or expensive equipment such as phones and TVs.

For many young people, socialising can mean going to the pub, or staying out late at night. Teenage Cancer Trust units allow visitors access whenever they like, as long as it does not disrupt other patients. This means that some friends even visit on the way home from a night out socialising or after work, which allows the patient to feel more involved in their friends' day-to-day lives.

# Being Connected

Other facilities on the wards such as computer consoles, pool tables and musical instruments encourage patients to socialise with their peers on the units, and also provide them with something to do when existing friends and family come to visit. Again this makes it more likely that friends of patients (who would otherwise find the hospital environment threatening and alien) will be more happy to visit the unit and offer support to their friends.

For younger patients whose parents will want to stay overnight, many of the Teenage Cancer Trust units provide comfortable facilities. Proper beds are made available alongside the patient beds and staff encourage parents to stay, rather than seeing them as problematic. This increased connectivity also aids the staff in their role by helping put the patients at ease and taking over some of the support and caring roles that staff would otherwise take on themselves.

By employing youth support coordinators for units Teenage Cancer Trust encourages patients to create new connections with their peers on the units. Many young people we spoke to who would otherwise have deliberately isolated themselves (in particular older teenagers), were encouraged to take part in organised activities by support coordinators,

including pizza or film evenings, as well as arts and crafts activities. All these activities help to provide a distraction from the day to day reality of cancer treatment.

Where possible, the units utilise outdoor space and use large windows to facilitate a connection between the patients and the outside world. To a certain extent this can be constrained by the space within

the hospital that the unit exists in. Infection control consideration can also make it difficult for the units to have open windows or

balconies. Nonetheless, designated garden space, outside of the units, can be used to overcome some of these issues.

## Considerations for the future

Similar to the control benefits, it is important that the needs of all patients are considered for this benefit too. For example, while older patients may greatly value having groups of friends visiting late in the evening, for others this may be tiring or distracting.

It is therefore important to ensure that noisier social activities take place in the social areas, rather than the bed area, and that activities do not become too disruptive.

A balance also needs to be struck between parents and children on the ward being able to spend the time they need together, and the young people having 'space' and access to other young people of their own age, in particular with peers on the ward itself.

Again, for normality to be maintained as much as possible, it may sometimes be necessary to facilitate this separation. To this end, dedicated spaces as well as kitchens need to be provided to allow parents to feel that they are close to their children, without necessarily being at their side all of the time.

# Best Medical Treatment and Care

Of course, in addition to the five benefit platforms, the primary reason that most patients are on the wards is to receive the best possible treatment and care for their illness.

The units facilitate best medical practice in several ways. Firstly, they bring together healthcare professionals who are specialists in teenage and young adult cancer care.

Rather than dealing with such cases on an irregular basis, it becomes the norm and as such they are likely to become more experienced in diagnosing and treating patients of this age range.

Bringing expert health care practitioners together can also aid the development of new treatments and care approaches.

Secondly, they are likely to become better attuned to dealing with young adult and teenage patients and be aware of the issues specific to this age group. As one patient put it:

*"STAFF ON THE TEENAGE CANCER TRUST UNIT JUST SEEMED MORE USED TO DEALING WITH PEOPLE LIKE ME AND I HAD MORE TRUST IN THEIR ANSWERS. THE STAFF ON THE OTHER WARDS WERE FINE BUT THEY JUST DIDN'T SEEM AS KNOWLEDGEABLE ABOUT IT ALL."*

Patient with experience of Teenage Cancer Trust unit and standard ward

The following sections explore each of the five

different benefit platforms that Teenage Cancer Trust units provide for the three user groups of patients, their friends and family, and for staff.

As mentioned above, Teenage Cancer Trust units provide benefits to patients, their friends and family, and staff across five main platforms. These platforms build on a foundation of providing best medical practice which for the vast majority is the most

important benefit. The way in which best medical practice is enabled and facilitated through these units is discussed below.

While these platforms are introduced as distinct categories, in reality they overlap with the needs, benefits and manifestations being interrelated. In addition, these benefit platforms help maintain a sense of 'normality' for those involved.

For some this means maintaining normality as far as possible, as it was prior to diagnosis and treatment, while for others it means adapting to, and maintaining their new normality, as discussed above. The following sections elaborate on this further and outline each of the five benefit platforms in terms of:

- > Defining what the benefit platform means in this context
- > Exploring why and how it is important to the different users of the units
- > Demonstrating how Teenage Cancer Trust units currently meet the stated need
- > Where applicable, assessing how this could be further improved and providing guidance on what to avoid

## Conclusion

This report has outlined the results from The Futures Company's work for Teenage Cancer Trust on Exploring the Impact of the Built Environment. The study found that within Teenage Cancer Trust units, design works hand in hand with other key elements such as equipment, staff and culture to deliver the kernel of their philosophy. Design itself is an enabler and is inseparable from these other elements.

At a high level, the key benefit delivered by this philosophy is the maintenance of 'normality' – manifested through the five key benefit platforms identified - Control, Comfort, Being Connected, Personalisation and Stimulation.

While the particular value of each of these platforms will be different to each patient, all are important and they are often mutually reinforcing.

As such, it is impossible to place the five benefit platforms into a hierarchy and it is perhaps best to view them as segments of an arch, whereby each segment reinforces the others and the removal of any individual section leads to a considerable weakening of the overall effect.

Overall it was found that the environment of the Teenage Cancer Trust units make a considerable difference to the experience of patients, friends and family and staff, through the maintenance of 'normality' and the increase in familiarity that results.

There are multiple benefits to the patients in both the short and long term. In the short term, as far as possible, the units allow patients

to spend their time in much the same way as they would if they had not been diagnosed with cancer. Generally, they have access to the equipment that they would have at home with few limitations on their usage.

They can maintain a high degree of control over their time with regards to what they do, when they get up, when and what they eat, and when they see friends and family. They have the freedom to surround themselves with pictures and decorations of their own choice, with shared spaces made as interesting and engaging as possible.

Proper facilities are put in place to allow their visitors to be as comfortable as possible and therefore more likely to visit – allowing the patient to continue to draw on their existing support networks at a time when they need them most.

Being on the units with their peers, rather than on adult or paediatric wards, means that patients are more likely to have things in common with the people that they are spending time with. It also means that they are more likely to meet other patients on the units who are going through a similar experience.

Rather than being the 'odd one out' on the ward, they are the norm and benefit from being able to discuss with, and learn from the other patients on the units. The benefits for the patients are perhaps best summed up by a patient who stated that:

*"IT JUST MADE WHAT WAS AN ABSOLUTELY HORRIBLE AND LIFE CHANGING EXPERIENCE A BIT MORE BEARABLE. I DREAD TO THINK HOW I'D HAVE COPEd IF I'D BEEN STUCK ON A NORMAL WARD."*

Patient on Teenage Cancer Trust unit

For the friends and family of patients, the benefits are split into two main areas – being more easily accommodated on the wards themselves; and

knowing that their friend, child or sibling is in the best possible environment and will be as comfortable and happy as possible at times when they are not able to be at their side.

Furthermore, rather than being limited and more passive with regards to how much they can help care for the patient, they can also take a more active role by cooking meals, playing games and watching TV together – normal things that friends and family members would ordinarily do.

For staff, Teenage Cancer Trust units change the focus of their roles. Rather than being perceived as ‘an enforcer of rules and regulations’ (as well as care givers), they can focus more heavily on becoming a ‘facilitator’ in enabling patients and supporting their recovery in a wider range of ways, beyond immediate medical care.

Their burden is also reduced as parents are able to take on some of the caring duties and the more informal philosophy creates a more positive atmosphere on the units. Patients are also more likely to engage with their treatment in a more positive manner which can improve their relationship with the staff.

“THE DIFFERENCE IN SOME OF THE KIDS IS JUST SO AMAZING WHEN YOU THINK BACK TO HOW THEY WERE WHEN THEY FIRST CAME IN. WHAT WE GIVE THEM HERE CAN'T COMPENSATE FOR WHAT THEY'RE GOING THROUGH BUT IT CAN CERTAINLY MAKE IT A BIT EASIER AND MORE PLEASANT.”

Nurse from Teenage Cancer Trust unit

This change in the focus of their role can help maintain staff morale in what is an inherently challenging role. As this report has highlighted, there are some areas where the Teenage Cancer Trust units could be further improved – in particular by focusing further still on very practical details, as well as giving consideration to all the senses.

However, overall there is little doubt from this study that, relative to standard wards, Teenage Cancer Trust units contribute hugely to improving the experience of all of those who come into contact with them.

