Re-defining cancer care with young people

Delivering Ambulatory Care to promote freedom, trust and agency

This resource communicates findings of a three-year study, funded by the National Institute for Health and Care Research (NIHR), which set out to explore and build evidence about an emerging model of cancer care in the NHS called Ambulatory Care.

It is an active and empowering guide that gives a voice to young people, using research evidence to centre their experiences in delivering ambulatory cancer care.

We don’t focus on specific cancer therapies and treatments. Instead, we outline ways that support young people’s autonomy and agency during their treatment and how to ensure a clinical safety net overnight and when they are out and about.

Introduction

What is it?

Why do it?

How to do it

Our research

Thanks

> “The concept of Ambulatory Care is gaining momentum as a transformative model for delivering cancer treatment. It represents an even greater shift towards more person-centred and self-managed care, empowering individuals to take an active role.”

Alison Finch
Principal Investigator

‹ ›

Overview

Treatments

How it works

Overview

In general terms Ambulatory Care (AC) is a model of healthcare that helps patients to receive medical treatment without staying in the hospital overnight. In the UK cancer setting, it refers to the hospital-led coordination and delivery of treatments that traditionally require an inpatient stay.

It was first piloted for adults in the UK in 2003 at University College Hospitals NHS Foundation Trust (UCLH) who extended it to teenagers and young adults in 2011, with the main aim of improving young people’s experience during their cancer treatment. Ambulatory Care is typically offered to young people who are having chemotherapy but can also support post-chemotherapy monitoring and other supportive care.

‹ ›

Treatments

Thanks to portable infusion pumps, some treatments can be given entirely in AC. Others, such as allogeneic haematopoietic (stem cell) transplant, combine AC with inpatient support for the most intensive period of supportive care and/or immunosuppression.

Some patients will need inpatient admission if they become clinically unwell (e.g. due to treatment related toxicity, side-effects or uncontrolled symptom management), if they would like to take a break from AC, or if they or their companion (the person accompanying them) are finding it difficult to monitor their condition on their own.

How it works

Patients can choose to opt into AC or opt out if it is the standard mode of treatment. Depending on the service set-up, they can either stay at home, in a patient hotel, a charity-funded home-from-home or commercial hotel accommodation, so long as they are less than an hour's travel time from the treatment centre.

Young people come to the AC unit once a day for a review or treatment and have 24-hour access to a senior cancer nurse. If they are over 18 they can use AC services without a companion (unless they're on chemotherapy that has a risk of neurotoxicity), although most young people choose to be supported by a relative, partner or friend overnight.

Outside the time that they are on the AC unit, young people are free to do what they would like to, for example, visit parks, cafes, the cinema or enjoy the quiet of their accommodation, according to how energetic and well they feel.

> "Being able to go back to somewhere more private at night is very nice. In the hospital you constantly have people coming into your room, whether it's cleaners, nurses, doctors, healthcare assistants checking your vitals, or the people bringing or taking away trays of food… you don't really feel you have that privacy at all."

a 24 year-old male

‹ ›

Introduction
What is it?
Why do it?
How to do it
Our research
Thanks

Introduction
Sense of our selves
Autonomy
Agency

Introduction

Young people are constantly changing, trying to find themselves, figuring out who they are and their place in society. We know that being told they have cancer can dislocate them from a sense of who they are, who they want to be and what's important in their lives.

Our research with young people shows that Ambulatory Care is not just an effective and safe way to deliver cancer treatment, but also a way of caring that helps foster their well-being, autonomy and agency.

We explain how young people's sense of autonomy is not fixed or experienced in isolation; it is experienced in relationship with others and connected to how AC is organised, and the infrastructure that you provide.

If you are a patient reading this resource, it may help you decide whether AC would suit you, or help you discuss with your care team how you would like to be supported.

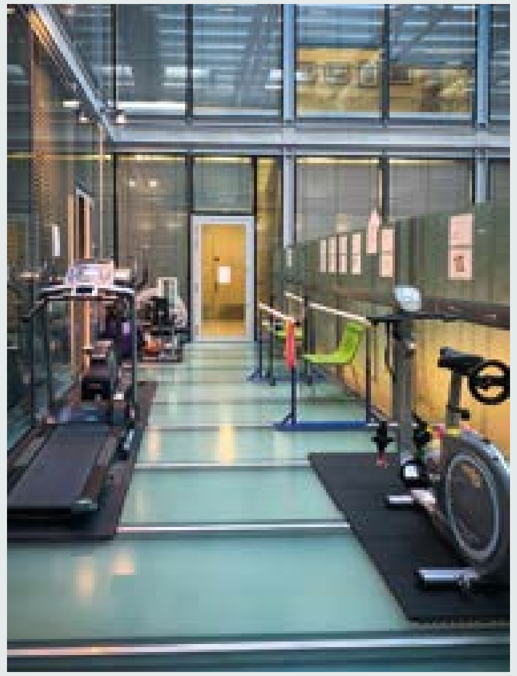
In this section we also include a link to photographs taken by young people as part of our research to describe their experiences and feelings about AC.

Introduction
Sense of our selves
Autonomy
Agency

Sense of our selves

Young people, aged 16–24, who took part in our research took mobile phone images of aspects of their day-to-day life in AC which they shared and discussed in peer interview conversations.

Click on the links below to view a selection of photographs that formed part of an exhibition that shared some of the themes arising from the research called *Sense of our selves*. The images, together with each young person's words illustrates how AC enables young people to feel rooted in a sense of themselves and autonomous.



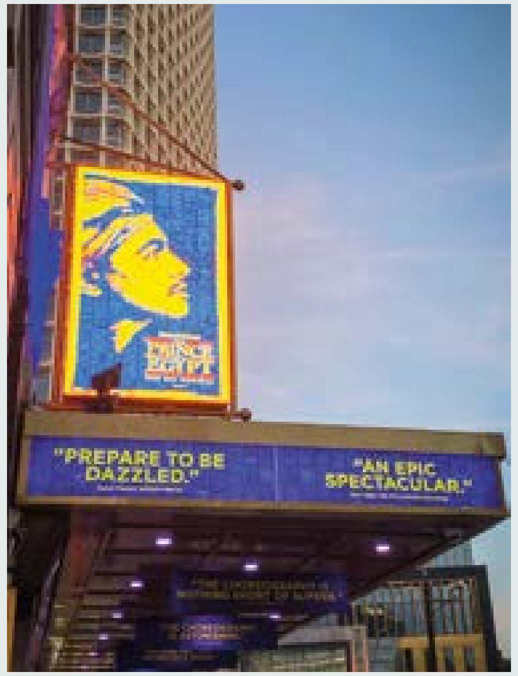
Sense of progress

Sense of constancy

Sense of privacy

Introduction
What is it?
Why do it?
How to do it
Our research
Thanks

Introduction
Sense of our selves
Autonomy
Agency

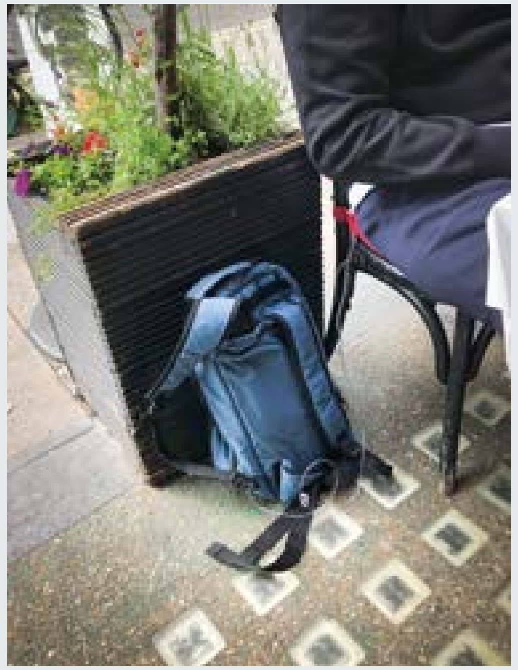


Sense of freedom

Sense of my life

Sense of appreciation

Sense of routine



Sense of normality

Sense of attachment

Introduction

Sense of our selves

Autonomy

Agency

Sense of choice

Sense of empowerment

Sense of scale

Sense of passage

Sense of...enjoy it before it melts

Sense of progress

"So there's a physio there that does exercise with you every day which is good, and you wouldn't tend to get that in a hospital.

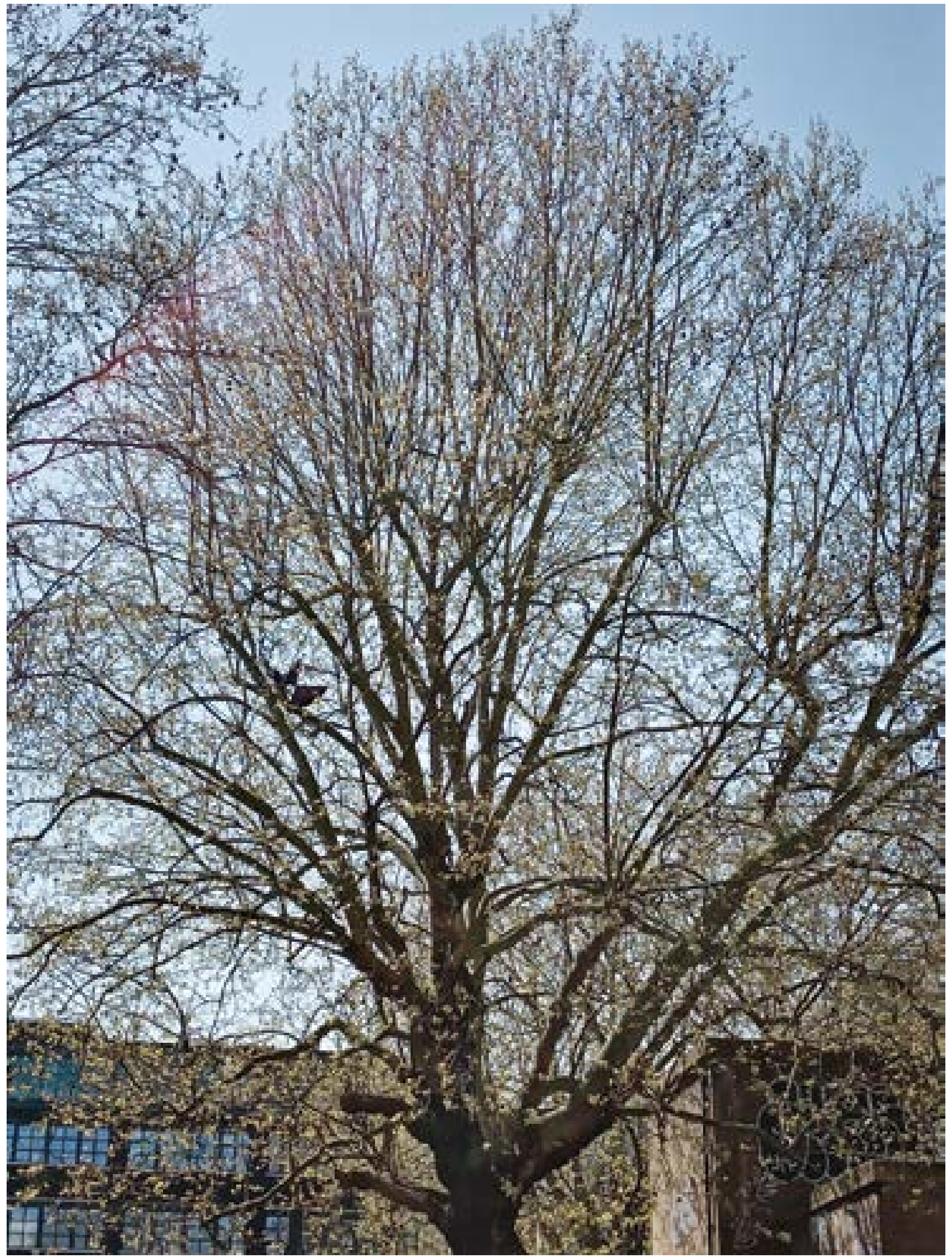
It helps me strengthen and progress my mobility. It shows that you're getting somewhere with the treatment and starting to recover."

From 'Sense of our selves' exhibition at UCLH, 2022

Sense of constancy

"It's a photo of just a random tree outside on the main road. When I would wake up in the morning, I'd see it. Whenever I'd go out for a walk, I could still see it.

During my chemo, it's something that didn't change. It signifies how going outside and just breathing fresh air is rejuvenating."



From 'Sense of our selves' exhibition at UCLH, 2022

Sense of privacy

“Having my own space is a big thing. Some people might want to get through their cancer treatment with loads of people around them. For me, not wanting everyone to know everything about me is a big thing.

Overall, Ambulatory Care gives you a sense of privacy. You have got your own space. I’ve got this room to me and my mum, and we’ve got a nice bed, with a duvet, and it’s just chill. We’ve got our own toilet. We don’t have to worry about sharing it with other people.”

From ‘Sense of our selves’ exhibition at UCLH, 2022

Sense of freedom

“I took this because it represents that you can do things when you’re in Ambulatory Care. Downside, I did have the backpack and you do have the 3-litre fluids with you, so you are carrying a lot but, yes, we had fun and we could go out and do things.

We did quite a bit of shopping before. Then we came and dumped all the stuff back into the room, had some dinner and then we went back out. It didn’t feel like I had cancer at the time. It didn’t feel like I had any treatment.”

From ‘Sense of our selves’ exhibition at UCLH, 2022

Sense of my life

"If people asked "What is your life?" I'd say "Being up a scaffold, building a loft, or playing football with my mates."

In Ambulatory Care you get to talk to the staff, the nurses, and my oncologist. They take an interest in what you actually do. It's not like "I'm just here to give you chemo, then you go."

You walk in and there's a bit of banter, like "Oh, Arsenal didn't play very well in the week," or something like that. It's nice that they remember."

From 'Sense of our selves' exhibition at UCLH, 2022

Sense of appreciation

"You just appreciate the little things. Although the door doesn't open, it is a really nice view. There are two sides of the hotel; East and West. I would tend to be in the room that shows the sunrise, which I love because I'm a morning person and I love the sunrise. It's amazing.

I tend to sleep with my curtain a little bit open because I like the natural light, you see the sunrise as you wake up. It's so beautiful and so calming. Then of course the hotel also offers breakfast, so you eat your breakfast with the sunrise."

From 'Sense of our selves' exhibition at UCLH, 2022

Sense of routine

“I think it’s very important to have something that you do every day - a routine that regardless of what situation you’re in or how you’re feeling, you have to do it. It’s like brushing your teeth - even if you don’t feel the greatest...”

From ‘Sense of our selves’ exhibition at UCLH, 2022

Sense of normality

“That was me just sat down for breakfast at a café. Rather than being on a ward and having all this medicine up on an IV stand or whatever, I have the option to take the pump and the medicine out with me.

Once I’d gotten used to it, it was quite easy to forget that it was there so I would just be able to sit down and have a normal meal with my family. Once I’d sat down, I’d taken the bag off, it felt almost normal.”

From ‘Sense of our selves’ exhibition at UCLH, 2022

Sense of attachment

“The backpack shower is a unique experience.

You are continuously attached to an intravenous drip in a rucksack for five days, and so where you go, it goes too.”

From ‘Sense of our selves’ exhibition at UCLH, 2022

Sense of choice

"This shows me doing a bit of shopping, which is definitely one of the massive benefits of the Ambulatory Care; the option to go out and go back to a bit of normality.

Often my mum and I will go out. This is us picking out some makeup. We've gone to Primark before and done a bit of clothes shopping. It's just nice to have that option really. It can be a very draining experience and it can get a bit mundane. Just something a bit normal, a bit different, just to split up the week."

From 'Sense of our selves' exhibition at UCLH, 2022

Sense of empowerment

"I felt like this photo represents me overcoming the fear of something that is constantly televised as scary and painful whilst educating myself. I know my blood pressure; I know my platelet levels. I feel like my relationship with my body and my relationship with medicine has come closer together.

The fear of something that is considered one of the scariest diseases to have doesn't feel so scary anymore, which is kind of crazy."

From 'Sense of our selves' exhibition at UCLH, 2022

Sense of scale

"Your eyes tend to lose focus when you're in hospital because everything is so close together... and these days, the only entertainment you have is either a book or a screen.

So, you're constantly looking at things that are very close together. Your sense of scale tends to become quite poor because you can't really focus on objects that are far away.

Going outside being able to look up and see the BT Tower, see something properly big, properly far away, let my eyes focus on something like that, it just felt good."

From 'Sense of our selves' exhibition at UCLH, 2022

Sense of passage

"I just feel like I've been going through a revolving door for the past few months.

You feel like you're at the beginning of starting something but there's so many doors you have to go through to get to the end. I just feel like it's more of a concept of "you will reach the end," but you probably have to go through a lot of doors to get to the end point."

From 'Sense of our selves' exhibition at UCLH, 2022

Sense of… enjoy it before it melts

"Even if the chemo muddled my sense of taste, it was quite freeing to be able to do something as simple as go out and get ice cream with my sister really.

It just felt like I wasn't trapped. I could do what I wanted to. I could still experience things that I would experience even when I was, you know, healthy. My sister had to literally run back with this one before it melted."

From 'Sense of our selves' exhibition at UCLH, 2022

Introduction
What is it?
Why do it?
How to do it
Our research
Thanks

Introduction
Sense of our selves
Autonomy
Agency

Promoting young people’s autonomy

Autonomy is often described as being able to exercise independence and informed choice. Fundamentally however, it is about self-care, and being able to do things that are important to you as a person. Helping young people do the things that matter to them is about supporting their *autonomy*.

Young people stand in a network of relationships with others. In Ambulatory Care, autonomy is not experienced or achieved individually – it is created in relationship with the healthcare team, together with the young person’s personal support network. In the AC context responsibilities are negotiated. They are often seen to pass back and forth between all three parties, while many become shared. What remains steadfast in assuring autonomy, however, is that everyone takes the young person’s lead.

In essence, young people’s sense of autonomy allows them to feel and be themselves.

Introduction
What is it?
Why do it?
How to do it
Our research
Thanks

Introduction
Sense of our selves
Autonomy
Agency

Ways in which we found Ambulatory Care supports young people’s autonomy include:

- Respecting privacy
- Developing a daily structure that builds on personal interests and usual routines
- Creating choices about the basics of daily life, for example, what to eat or when to rest
- Promoting activity and mobility
- Accessing physio- or occupational therapy in a less clinical setting with a focus on maximising independence
- Feeling knowledgeable and informed about cancer treatment and the monitoring needed to look after oneself
- Enabling self-management of medications, building overall skills and confidence, including times in between treatment at home
- Feeling part of wider society, through spending time outside in the community
- Trusting oneself, and being trusted about one’s personal judgement, capacity and resourcefulness

‹ ›

Other factors we found that may affect young people's autonomy include:

- How physically able they are, which may change during cancer treatment, particularly if surgery is involved
- Accessibility of the residential setting
- Energy levels to look after themselves, which may also fluctuate, depending on the treatment cycle or symptoms such as nausea.
- Money to do things that we know young people enjoy during their AC stays, such as meals out or trips to the cinema
- The availability of a companion, willing and able to help share care requirements
- Access to a dedicated space on the AC unit, where they can meet other young people and members of the healthcare team.

Supporting young people to exercise their agency

The essence of AC is that it is not rigidly structured. As a young person receiving treatment in AC, you stay in a community setting from which you move out daily to access healthcare. This sits in contrast to the inpatient ward where, even within a dedicated age-appropriate setting, you fulfil a more passive role, with care coming to you.

“Ambulatory Care is about ownership, it’s your thing”, said a 17 year-old who took part in the research. What is enabled in the AC setting, without many of the organisational structures and routines of the inpatient ward, is that young people can exercise their agency. By this we mean their innate capacity to be more self-governing and help take care of themselves. Agency is fostered through the infrastructure of a clinical safety net, education and partnership working. It is enabled in the space that is created through being less monitored or observed during treatment – a space in which young people can draw on their own developing knowledge, their resourcefulness and trust in themselves and others, to help direct their experiences of cancer treatment.

> "It's poignant to learn how this model of care retains and promotes a young person's agency - such a core concept at this life stage, when striving for and practising control over your life begins and develops."

Louise Soanes
Chief Nurse, Teenage Cancer Trust

Introduction

Setting up an Ambulatory Care service depends on your motivations and resources. For some it may be pressure on hospital beds or the need to admit young people to an adult ward, but it can also be your committment to improve patient experience.

Either way, the key components of AC are:

› **a clinical safety net**

› **creating or identifying comfortable spaces inside and outside of hospital**

› **providing young people with support from staff, companions and the outside world**

› **providing patient choice**

Introduction
What is it?
Why do it?
How to do it
Our research
Thanks

Introduction
Critical factors
Getting started
A clinical safety net
Where to stay
Practical tips
AC option for all

Twelve critical factors

Our research findings from young people, their companions and staff identified twelve factors that are needed to ensure AC works effectively:

1. Assurance of a well-designed 24/7 **clinical safety net**
2. **Choice** between Ambulatory Care or standard inpatient treatment
3. A **welcoming and comfortable** AC unit and area with a separate recreational space, if possible
4. A **relaxed place** to stay outside of the hospital
5. **An easy commute** to the treatment centre
6. Ability to pass time in **private**, unobserved by the healthcare team
7. Time spent **outside**, in green spaces and wider society, supporting physical and mental health
8. Support to feel **independent** and keep a sense of oneself
9. **Partnership** working between the young person, their companion and members of the healthcare team
10. Keeping an **organisational** structure to AC, for example ensuring young people know what time they need to take their medication and attend daily on the unit
11. For most people, the presence, practical and emotional support of a **companion**
12. **Food** – choice about what and when to eat, together with the comfort of familiar meals. Ensuring access to food storage and hot meals so they feel cared for and as healthy as possible.

Introduction
What is it?
Why do it?
How to do it
Our research
Thanks

Introduction
Critical factors
Getting started
A clinical safety net
Where to stay
Practical tips
AC option for all

Getting started

Project lead

When developing an AC service, dedicated set-up time together with the allocation of resources is usually needed for the best chance of success. It is often beneficial to have a dedicated clinical project lead. Depending on the size of your intended service, or if a project manager is not feasible, project coordinator assistance as a minimum will be required, helping ensure the right infrastructure is in place for AC.

Team and sponsorship

Start by understanding the experience and resources in your team and get project sponsorship from a senior or executive level leader. The transition of cancer protocols from inpatient to AC requires both pharmacy time and expertise at the set-up stage, which will need to be allocated and resourced. Developing or adapting operational protocols, risk assessments and procedures for your service will also require relevant expertise; it is often not feasible for healthcare professionals to deliver on these without dedicated time if they are working in busy clinical roles.

While AC is largely a nurse-led service, young people will still need to access the multidisciplinary team as they would if they were an inpatient.
Remaining active and independent is critical to people's positive experiences of AC; it brings physical as well as psychological health benefits. Yet tailored professional support and interventions are needed to maximise the benefits of AC – which will need to be considered as part of workforce planning. While AC is largely a nurse-led service, it is critical that young people retain access to the multi-disciplinary team in the same way they would if they were an inpatient. This includes the physiotherapy and occupational therapy team who need to assess the residential setting, and decide whether any aids, adaptations or specific provisions are required.

The clinical setting
A dedicated, relaxed and open-plan non-treatment area for young people helps them connect with others who share similar experiences, fosters peer support and facilitates a space to meet their companions and friends, rather than feeling a need to leave immediately following daily review or treatment. It also, critically, ensures that there is space to meet with a dietician or clinical nurse specialist or to receive physiotherapy, occupational therapy or psychological support in a less clinical environment.

Introduction
Critical factors
Getting started
A clinical safety net
Where to stay
Practical tips
AC option for all

The AC unit where our research took place integrates AC, day care and outpatients across the entire floor of a cancer centre. You may not have the same space or service configuration, and will need to agree the location of your AC clinical hub and other support services.

Equipment
When considering the resources required to run an AC service, you will need to factor in portable infusion pumps that give continuous infusions and the option for intermittent boluses, together with a backpack or bag to store and transport them in. This will most likely involve a significant financial outlay, but is critical to be able to get going. Other equipment needed may include access to wheelchairs, bathing aids or things like ensuring every patient has a thermometer.

Overnight stays
You need to consider where patients will stay overnight. This may include charity funded or hotel accommodation close to the hospital, or you may decide to start with patients who ambulate from home. Proximity and easy access to the hospital in case of need is important however, irrespective of the setting. Members of the multi-disciplinary and infection control team should be consulted about the set-up, as appropriate. If not at home, security arrangements will need to be considered in the event that young people need to make their way to the hospital during the night.

Food
Food is also central to young people's positive experiences of AC. Input from the dietician will be important so that all patients have a range of options for healthy eating. This may include eating out in cafes, shopping in supermarkets or ordering food deliveries (all promoting choice, autonomy and helping time pass enjoyably). Food can also be an expensive addition to care, so make sure that people are not financially or nutritionally disadvantaged by choosing AC.

A clinical safety net

Underpinning AC is a clinical safety net. Young people, companions and healthcare professionals who took part in the research all described four components as critical both to the safe running and their confidence in AC:

1. Staying within proximity to the hospital

To be eligible for AC, in case of emergencies, there is a safety requirement to live within one hour's travel distance of the hospital overnight. Staying within walking distance of the hospital can be preferred during initial AC stays to help build confidence or, more generally, if symptoms such as fatigue or nausea make daily car journeys to the hospital feel too difficult.

Depending on the service set-up, options may include a patient-focused or commercial hotel, a self-catering apartment, a charity-supported home-from-home, or staying at one's own home. There are pros and cons for each and the decision about where to stay should be taken by the patient.

2. 24-hour telephone advice line

Access to advice from experienced cancer professionals day and night must be ensured. A mobile phone is held by the AC team during the day which, following a detailed handover, transfers to a senior nurse on the inpatient ward overnight.

3. Education to monitor themselves during treatment

Provision of information and educational material about the responsibilities that come with AC and when to get in touch for advice is vital. Advice on practical monitoring skills together with how to remain vigilant around health status helps assure safety, builds confidence and facilitates self-appraisal of suitability for AC.

4. Direct access to clinical care and support of the multidisciplinary team

If unwell, young people have direct access to a bed in the inpatient ward which is kept available in case of need, avoiding lengthy waits in the emergency department. This also means that young people are seen by a team who understands their cancer treatment, and they receive prompt clinical care.

It's important to remember that young people would otherwise be inpatients. Ensuring access to the full complement of the multidisciplinary team in AC ensures support for their physical and mental health.

When receiving AC, young people say they feel reassured knowing that the inpatient ward team is there for times when they seek advice, require closer monitoring or if they become unexpectedly unwell. The inpatient ward is critical to the safety net of AC.

Introduction
What is it?
Why do it?
How to do it
Our research
Thanks

Introduction
Critical factors
Getting started
A clinical safety net
Where to stay
Practical tips
AC option for all

Where to stay

Hotel

A patient or commercial hotel offers a relaxed non-clinical setting. Staying somewhere comfortable, where there is thought given to the comfort of a young person and to the person accompanying, can contribute to everyone feeling cared about. A hotel breakfast was "the nicest thing", said one young person we spoke with. Having a private bathroom, we found, can truly respect the dignity of young people.

With less responsibility for all concerned than at home, the hotel environment can often result in the passing of more quality time between young people and their companions.

Self-catering apartment

For AC stays of a week or more, a self-catering apartment offers not only offers more space than a hotel room, but having somewhere to call your own has other benefits too. A fully equipped kitchen reduces reliance on takeaways, keeping costs down, as well as providing somewhere to cook nourishing and favourite meals.

Typically, there may be two bedrooms or a sofa bed in the living area – allowing a young person and their companion to each spend some time on their own. Depending on your service set-up it may be possible for a family dog to stay too!

Introduction
Critical factors
Getting started
A clinical safety net
Where to stay
Practical tips
AC option for all

“At the end of the day it isn’t home,” said one of our research participants, and to them, this was a good thing. They associated their stays with progressing through treatment before returning to the constancy of home.

Home-from-home
A charity home-from-home can offer the best of both worlds for some families. A comfortable room, shared kitchen, support of staff and common areas to rest or meet others from the cancer community may feel like a step up from a hotel or apartment for those seeking a more communal and supported experience, while offering privacy and much of the independence of home.

Home
For others, the comforts of home cannot be recreated elsewhere. Being able to sleep in your own bed at night, surrounded by familiar things, is the ultimate preference for some young people. By contrast, some might prefer to keep their home protected from the most intense parts of their cancer treatment. Practical tips

Young people, their companions and healthcare professionals who took part in our research gave us many practical suggestions about what is needed when developing AC:

‹ ›

Being at home can promote independence. Staying at home can also mean that the supportive role fulfilled by a companion can be shared with other family members or friends – providing a break for everyone.

How far families live from the cancer centre is a factor, however, that can influence how confident people feel ambulating from home. Symptoms such as fatigue or nausea might make daily travel feel too difficult or families may worry about distance in the event of needing to make an unplanned trip to hospital.

When starting out in AC, families might feel apprehensive about AC from home. With more experience, however, they often feel more confident about this option.

Practical tips

Young people, their companions and healthcare professionals who took part in our research gave us many practical suggestions about what is needed when developing AC:

› Create an AC **welcome pack**, setting out the full range of facilities available, together with how to access them

› Ensure information about **parking permits** and other dispensations is shared

› Consider **security arrangements** to ensure that young people can be accompanied to the hospital when staying in hospital or hotel accommodation if needing clinical review at night

› If staying in a hotel, ensure they have a **fridge** for groceries and cool drinks and access to a freezer if possible

› Ensure there is the option to select or order a **free hot meal** for families who would like it

› Provide a **basic grocery supply** (milk, bread, fruit) on an opt-in basis, at no charge to families

› Provide a means to prepare and heat simple **food**

› Offer access to **laundry** facilities

› Ensure bedroom **fire doors** work with wheelchairs without the need for extra assistance

- Review the **bathroom set-up** and provide hooks to hang pump backpacks while showering
- If more than one bathroom type is available, make sure the healthcare team and families know how to request a **wet room or bath**, according to preference and access needs.
- Consider the feasibility of providing an **ice machine or cold compresses** for the weeks following surgery, if relevant to your clinical area.

A hybrid AC model for everyone

While our research evidenced many benefits of AC to young people's experiences of cancer treatment, the service may not be open to all. For example, being able to communicate in English is currently a safety requirement of AC. Alternatively, a patient's treatment protocol may not be suitable, or have transitioned to an AC basis.

We recommend that all young people should be able to experience some of the benefits of AC, even as inpatients, by embedding principles that promote autonomy and agency. This could include aspects of self-medication or, where possible, spending time off the ward.

For these people, for services piloting AC, or where a service is not currently feasible, a hybrid model that makes use of portable infusions will enable many more people to spend time away from the ward, returning to an inpatient bed overnight.

> “From the outset we designed the research as a participatory endeavour to build knowledge with, alongside and for the teenage and young adult cancer community.”

Alison Finch and colleagues

Introduction
What we did
What we found
Staff evidence
Key learning

Introduction

This research set out to understand experiences of Ambulatory Care (AC), a relatively novel service in the NHS. We wanted to know how well teenage and young adult AC meets the care needs and supports the well-being of young people.

We carried out our participatory research within the young people's AC service at University College London Hospitals NHS Foundation Trust, with eighteen young people aged 16–24, thirteen companions and twelve staff members taking part. Young people and companions with personal experience of NHS cancer services joined the research team, getting involved in the conduct of the study and bringing their lived experience to light throughout. Together we formed a Community-of-Inquiry that met regularly over a three-year period, taking on different roles and responsibilities in the conduct of the research.

Most young people who took part in the research stayed in our hospital hotel. Some stayed at home or in a hospital apartment overnight. We wanted to hear from young people, the person accompanying them and members of the healthcare team about how they experienced the service; how it helped young people cope with cancer; to identify possible improvements; and to build evidence about AC. Our ultimate aim is to help other NHS Trusts deliver this emerging model of cancer care.

Introduction
What we did
What we found
Staff evidence
Key learning

What we did

Very early on, before the study was designed, we consulted with young people and companions who had experience of AC about what they thought was important for us to research. These contributions subsequently formed the basis for a successful fellowship grant application to the NIHR.

The study posed five questions which were answered through a scoping review of the literature, semi-structured interviews with health professionals, photo-guided peer interviews with young people and a three-way exploratory conversation with their companions.

Following preparation and training, our Community-of-Inquiry became actively involved in the research; this included facilitating interviews and engaging in participatory data analysis.

Introduction
What we did
What we found
Staff evidence
Key learning

What we found

Our research found that Ambulatory Care positively contributed to young people's experience of receiving cancer treatment. It retains aspects of life that are important to young people in ways that not only supports their independence, but helps them to feel like 'themselves', autonomous and less defined by their clinical diagnosis.

Patient evidence

Young people said they felt safe in AC. Moreover, they valued the freedom, choice and independence that AC enabled, as well as its respect for their privacy. Privacy facilitated sleep, rest and passing time with friends and family. In addition, some young people appreciated that the energy required to witness or hear about others' cancer experience was limited to times when they were at the AC unit.

AC helps retain important things in life – eating out, home friendships and connections with society. It helps minimise changes to young people's lives by keeping daily routines and social contacts.

Everyone who took part in our research also had experience of inpatient care. They described their AC experience in contrasting ways, explaining how it contributed to more positive mental and physical health.

All the young people we spoke to usually lived in the family home. Irrespective of whether they stayed in a hotel or their own home for AC, every young person welcomed and appreciated their companion's practical and emotional support. While it was found to be a necessity for those in a wheelchair or on crutches, being accompanied reduced loneliness and supported young people's well-being and confidence.

Companion evidence
Companions of all ages felt purposeful and appreciated the opportunity to fulfil a definitive role, often countering feelings of helplessness. Being with their young person also often helped manage their own worries about how their loved one was doing; as they could see for themselves. Companions, particularly parents, also felt supported from other companions they met on the AC unit. Away from the unit all companions valued spending quality time with their young person in private – whether watching TV in their room or visiting the shops.

At times, however, companions found their role emotionally difficult. They wanted the healthcare team to take more interest in their psychological well being, together with clearer signposting to available support. They sought validation for the practical, emotional and surveillance responsibilities that they provided and wanted to be recognised by the healthcare team – as not only contributors to care, but as people with their own emotional and support needs too.

Staff evidence

Every member of the healthcare team was a strong advocate for AC. ‘Freedom’, ‘independence’ and the opportunity to experience greater ‘normality’ were seen as the key benefits of the service, with many describing how AC embedded principles of age-appropriate care.

As patients spend less time with staff in AC, the healthcare team rely on young people and companions to share responsibility for monitoring symptoms, completing checks and telling them if measurements are out of range or they have other worries. The research found that contact time with AC staff sometimes focused on monitoring or technical aspects of care and recommended that staffing levels and ways of working need to allow for more holistic conversations to maximise person-centred care.

Key learning from the research findings

- The importance of young people's autonomy in retaining a sense of 'oneself' during cancer treatment
- The role that agency plays in the positive experiences of AC, through its respect for the innate capacities of young people
- If prepared and educated, young people, together with their companions, adjust well to the responsibilities of AC
- Young people themselves actively contribute to the safety of AC, through their active self-surveillance and, over time, their self-knowledge about how they respond to treatment
- Ambulatory Care can support young people's mental health and perceptions of well-being
- An open-plan recreational area on the AC unit plays an important role in peer support, together with feeling part of a supportive cancer community
- Being accompanied overnight is often critical in negotiating the responsibilities of AC and young people's confidence to ambulate
- Companions value the opportunity to play an active role in care although wish for greater recognition of their contributions, alongside access to psychological support

- When preparing young people and their companions to ambulate, it is important they understand which responsibilities remain with the healthcare team, to avoid misconceptions or a heightened sense of accountability
- Delivery of age-appropriate care encompasses young people's support network which may include AC companions who are young people themselves
- The positive contribution that a youth support coordinator makes to both young people and companion experiences
- To promote equity, information shared about support groups, food options, parking permits etc. should be standardised to promote equity

Finally, as an AC service grows in size and complexity, there must be commensurate investment in the AC workforce to ensure that nurses and other healthcare professionals have capacity to work beyond the delivery of safe technical care, and embed a holistic, person-centred approach.

Introduction

What is it?

Why do it?

How to do it

Our research

Thanks

Thanks

Related content

Download PDF

Share this resource

This research was funded by NIHR as part of their Clinical Doctoral Research Fellowship programme [NIHR-ICA-CDRF-2018-04-034] and was led by Alison Finch, a cancer nurse, as principal investigator. The chief investigator was Professor Rosalind Raine, NIHR Senior Investigator and Director of the NIHR ARC North Thames.

We acknowledge and thank all the young people, companions and healthcare professionals who took part. The research would not have been possible without the contribution of co-researchers (in alphabetical order) Sadhia Ali, David Chang, Emma Haslam, Michela Quecchia, Robert Rietz and Kristy Wang who, over a three-year period, practically engaged in every stage of the research process.

Alison would also like to acknowledge the contributions of Silvie Cooper, Alana Evans, Faith Gibson, Lauren Jordan, Darren Sharpe, Rachel M Taylor and Rosalind Raine, together with charities Teenage Cancer Trust and Young Lives vs Cancer who collaborated in this work.

How to cite
Finch, A. (2023) Re-defining cancer care with young people: delivering ambulatory cancer care to promote freedom, trust and agency. Available at www.arc-nt.nihr.ac.uk.

UCL

NHS
University College London Hospitals
NHS Foundation Trust

FUNDED BY
NIHR | National Institute for Health and Care Research

TEENAGE CANCER TRUST

YOUNG LIVES vs CANCER

Publication design by

Design Science

Thanks

Related content

Download PDF

Share this resource

We hope that this resource will be of practical use. If you have experience of delivering or receiving young people's Ambulatory Care and would like to connect with a wider clinical and academic community, do get in touch.

The content of this resource is based on Alison's PhD thesis Experiences of teenage and young adult ambulatory cancer care: Community-Based Participatory Research to inform service provision

You can learn more about this research and the benefits of Ambulatory Care to young people's experience of cancer treatment in this blog: Ambulatory Care: Empowering Patients and Shaping the Future of Healthcare

To find out more about the development of Ambulatory Cancer Care in the UK see: The Development of Ambulatory Cancer Care in the UK: A Scoping Review of the Literature

This content will be updated as more publications are made available.