

This is only a start

This leaflet is designed to get you to start thinking about adult services and the transition process.

For every person, this process will be slightly different but your healthcare team should be able to provide you and your family with information about it.

By talking about transition early, you should have plenty of time for discussions and questions, ensuring that you are fully prepared when the time comes to make the move to adult services.



You may like to use this section to jot down any questions you have about your transition.

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My key worker is:

Contact details:

The Ready Steady Go materials were developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42. Users are permitted to use 'Ready Steady Go' and 'Hello to adult services' materials in their original format purely for non-commercial purposes. No modifications or changes of any kind are allowed without permission of University Hospital Southampton NHS Foundation Trust.

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Transition: moving into adult care

Information for young people and families



What is transition?

In healthcare, we use the word “transition” to describe the process of preparing, planning and moving from children’s to adult services.

Transition is a gradual process that gives you, and everyone involved in your care, time to get you ready to move to adult services and discuss what healthcare needs you will require as an adult.

This includes deciding which services are best for you and where you will receive that care.

Transition is about making plans with you - and not about you.

We understand that moving away from a team of doctors and nurses that you have been with for many years can be scary but hopefully, by getting involved in the transition process, you will feel more confident and happier about the move.

Why do I have to move?

As you get older, you will find that some of the things you want to discuss or some of the care you might need is not properly provided by our children’s services.

Adult services are used to dealing with all sorts of issues that may arise, such as higher education, travelling, careers and sex.

You may also find that you would prefer to be seen in a more grown-up environment, rather than the usual children’s departments or wards.

When do I have to move?

There is no exact time that is right for everyone.

The purpose of this leaflet is to get you thinking about moving on and preparing for it.

Your doctors and nurses may have an idea about when they feel that you might be ready but it is important that you are involved in that decision.

Can I choose where I move to?

Part of the transition process should be helping you to look at where your ongoing healthcare needs can best be met and how this will fit in with your future plans.

Your consultant or family doctor (GP) will be able to give you information to help you make the best decision.

If there is a choice of places, it is a good idea to visit all of them and then decide which is best for you.

Who can help me get ready?

Your healthcare team will be able to give you information and support about moving on.

They can help you get ready for adult services by:

- Teaching you about your condition or illness, its treatment and any possible side effects
- When you are ready, seeing you on your own for part of the clinic appointment and working towards seeing you on your own for the whole clinic appointment
- Making sure you know when to get help and who to contact in an emergency
- Helping you understand how your condition or illness might affect your future education and career plans
- Making sure you know about the support networks available
- Making sure you understand the importance of a healthy lifestyle, including exercise, diet, smoking and sex.

Your family

Your parents or carers have been really important in looking after your health and will be able to give you lots of helpful advice.

While you are in the process of transitioning, your parents will still be very involved in your care and their role is still important.

Try to talk to them and your health care team about how you feel about moving on to adult care and any questions or concerns you might have.

Also try to discuss practical issues relating to your health, such as getting to appointments, obtaining repeat prescriptions and asking questions in clinic.

While transition is all about you, it is important to realise that your parents may also be finding the process difficult as now they are handing over the responsibility to you.

This can be hard for many parents and they may have worries of their own.

You may find talking to them about your feelings, and allowing them a chance to tell you how they feel, will help you all through the process.

Questions you may like to discuss with your healthcare team:

- What is the plan for my transition?
- When am I moving to adult services?
- Can I choose which adult service I move to?
- What is different about the adult service?
- Can I meet the adult staff before I leave children’s services?
- Can I visit the adult service to look around?
- Are there any young people I can talk to about moving to adult services?
- What do I need to know before I move to the adult service?
- When can I start getting more involved in my health care?
- How will my condition affect my future, such as my education and employment prospects?

Transition programme



Name: _____ Hospital no: _____

Address: _____ DOB: _____

_____ Transition start date: _____

_____ School/college: _____

Home tel no: _____

Email: _____ Mobile no: _____

Diagnosis: _____

Target date for transfer adult services: _____

Discharge summary completed: _____

Resources: _____ Date: _____

Transition leaflet for young people _____

Transition leaflet for parents/carers _____

Other (please specify) _____

Offer copy of clinic letters _____ Date: _____

MDT involvement _____

Youth worker _____

Social worker _____

Psychology _____

Specialist nurse _____

Dietitian _____

Other _____

Key worker _____

Adult unit team contacts _____

Date of planned visit to adult unit _____

Transition programme

(K) KNOWLEDGE

	R	S	G
1. Describes condition, effects and prognosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Understands medication purpose and effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Understands treatment purposes and effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Knows key team members and their roles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(S) SELF ADVOCACY

1. Part/whole clinic appointment on their own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Knows how to make appointments/alter appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Understanding of confidentiality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Orders repeat prescriptions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Takes some/complete responsibility for medication/other treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Knows where to get help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(H) HEALTH AND LIFESTYLE

1. Understands importance of diet/exercise/dental care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Understands impact of smoking/alcohol/substance use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Understands sexual health issues/pregnancy/STDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(A) ACTIVITIES OF DAILY LIVING

1. Self care/meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Independent travel/mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Trips/overnight stays away from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Transition programme

(V) VOCATIONAL

	R	S	G
1. Current and future education/impact of condition on career plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. School attendance and performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Work experience and how to access careers advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Outside activities and interests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Disclosure to school/employer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(P) PSYCHOSOCIAL

1. Self esteem/self confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Body/self image	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Peer relationships/bullying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Support networks/family/disclosure to friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Coping strategies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(T) TRANSITION

1. Understands concept of transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Agrees transition plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Attends transition clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Visits adult unit (if appropriate)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Sees GP independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Ready Date _____ Signature _____

Steady Date _____ Signature _____

Go Date _____ Signature _____

The Ready Steady Go transition programme - Getting Ready

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you. **Please answer all questions that are relevant to you and ask if you are unsure.**



Name:

Date:

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I can describe my condition			
I know when to take my medications, names, doses, how often, etc			
I know who's who in the medical and nursing team.			
I understand the differences between paediatric and adult health care			
I know about resources that offer support for young people with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel ready to start preparing to be seen alone for part of the clinic visit in the future			
I ask my own questions in clinic			
I have heard and know about 'Ask 3 Questions'			
HEALTH AND LIFESTYLE			
I understand it is important to exercise for my general health and condition			
I understand the risks of alcohol, drugs and smoking to my health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I develop e.g. puberty			
I know where and how I can access information about sexual health			

The Ready Steady Go transition programme - Getting Ready

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
DAILY LIVING			
I can look after myself at home in terms of dressing and bathing/showering etc			
I can make my own snacks/meals			
I am able to be away from home overnight.			
SCHOOL AND YOUR FUTURE			
I am managing at school e.g. getting to and around school, school work, PE, friends, etc			
I know what I want to do when I leave school			
LEISURE			
I can use public transport and access my local community, e.g. shops, leisure centre, cinema			
I see my friends outside school hours			
MANAGING YOUR EMOTIONS			
I know how to deal with unwelcome comments/ bullying			
I know someone I can talk to when I feel sad/ fed-up			
I know how to deal with emotions such as anger or anxiety			
I am happy with life			
TRANSFER TO ADULT CARE			
I understand the meaning of 'transition' and transfer of information about me			

Please list anything else you would like help or advice with:

Thank you

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The Ready Steady Go transition programme - Steady

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.

Please answer all questions that are relevant to you and ask if you are unsure.



Name: _____

Date: _____

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I understand the medical terms/words and procedures relevant to my condition			
I understand what each of my medications are for and their side effects			
I am responsible for my own medication at home			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
I know what each member of the medical team can do for me			
I understand the differences between paediatric and adult health care			
I know about resources that offer support for young people with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own for some/all of each clinic visit and to ask my own questions			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the risk of drugs, alcohol and smoking to my health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I develop e.g. puberty			
I know where and how I can access information about sexual health			
I understand the implications of my condition and drugs on pregnancy/parenting			

*See leaflet or www.advancingqualityalliance.nhs.uk/wp-content/uploads/2013/04/BrochureFinal25.10.12.pdf

The Ready Steady Go transition programme - Steady

Knowledge and Skills	Yes	I would like some extra advice/help with this	Comment
DAILY LIVING			
I can look after myself at home in terms of dressing and bathing/showering etc			
I can make my own snacks/meals			
I know how to plan ahead for being away from home, overseas, trips, e.g. storage of medicines and vaccinations			
SCHOOL AND YOUR FUTURE			
I am managing at school, e.g. getting to and around school, school work, PE, friends, etc			
I know what I want to do when I leave school			
I have had work experience			
I am aware of any potential impact of my condition to my education and/or work opportunities			
I know who to contact for careers advice			
LEISURE			
I can use public transport and access my local community, e.g. shops, leisure centre, cinema			
I see my friends outside school hours			
MANAGING YOUR EMOTIONS			
I know how to deal with unwelcome comments/ bullying			
I know how to deal with emotions such as anger or anxiety			
I am happy with life			
I am comfortable with the way I look to others			
TRANSFER TO ADULT CARE			
I understand the meaning of 'transition'			
I am aware of the plan for my medical care when I am an adult			
I would like more information about visiting the adult service I might be attending			

Please list anything else you would like help or advice with:

Thank you

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The Ready Steady Go transition programme - Go

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.

Please answer all questions that are relevant to you and ask if you are unsure.



Name:

Date:

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I am confident in my knowledge about my condition and its management			
I understand what is likely to happen with my condition when I am an adult			
I look after my own medication			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own in clinic			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the effect of smoking, drugs or alcohol on my condition and general health			
I understand what appropriate eating means for my general health			
I know where and how I can access providers of reliable accurate information about sexual health			
I understand the implications of my condition and drug therapy on pregnancy/parenting (if applicable)			
DAILY LIVING			
I am independent at home – dressing, bathing, showering, preparing meals, etc			
I can or am learning to drive			

*See leaflet or www.advancingqualityalliance.nhs.uk/wp-content/uploads/2013/04/BrochureFinal25.10.12.pdf

The Ready Steady Go transition programme - Go

Knowledge and Skills	Yes	I would like some extra advice/help with this	Comment
DAILY LIVING (CONTINUED)			
I know how to plan ahead for being away from home, overseas, trips e.g. storage of medicines, vaccinations			
I understand my eligibility for benefits (if applicable)			
SCHOOL/CAREER/YOUR FUTURE			
I have had work/ volunteering experience			
I have a Career Plan (please specify)			
I am aware of the potential impact (if any) of my condition on my future career plans			
I know how and what to tell a potential employer about my condition (if applicable)			
I know who to contact for careers advice			
LEISURE			
I can use public transport and access my local community, e.g. shops, leisure centre, cinema			
I see my friends outside school hours			
MANAGING YOUR EMOTIONS			
I know how to deal with unwelcome comments/ bullying			
I know someone I can talk to when I feel sad/fed-up			
I know how to cope with emotions such as anger or anxiety			
I would like more information about where I can get help to deal with my emotions			
I am comfortable with the way I look to others			
I am happy with life			
TRANSFER TO ADULT CARE			
I understand the meaning of 'transition' and transfer of information about me			
I know the plan for my care when I am an adult			
I would like more information about an orientation visit to the adult service I will transfer to for my adult care			

Please list anything else you would like help or advice with:

Thank you

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Ready Steady Go Transition Programme



Name: _____ Hospital no: _____

Address: _____

DOB: _____

Ready Steady Go/Hello start date: _____

College/work: _____

Home tel no: _____

Email: _____ Mobile no: _____

Diagnosis: _____

Resources (please specify): _____ Date: _____

Offer copy of clinic letters _____ Date: _____

MDT involvement

Youth worker _____

Social worker _____

Psychology _____

Specialist nurse _____

Dietitian _____

Other

Key worker _____

Ready Steady Go Transition Programme

(K) KNOWLEDGE

	R	S	G	H
1. Describes condition, effects and prognosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Understands medication/treatment purpose and effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Takes some/complete responsibility for medication/other treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Orders repeat prescriptions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Knows how to make/alter appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Knows key team members and their roles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Knows where to get help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(S) SELF ADVOCACY

1. Part/whole clinic appointment on their own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Understanding of confidentiality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Understands their role in shared decision-making with the healthcare team e.g. Ask 3 Questions*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*See leaflet or www.advancingqualityalliance.nhs.uk/wp-content/uploads/2013/04/BrochureFinal25.10.12.pdf

(H) HEALTH AND LIFESTYLE

1. Understands importance of diet/exercise/dental care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Understands impact of smoking/alcohol/substance use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Understands how their condition can affect how they feel and function e.g. sexual function, fertility, fatigue etc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Understands sexual health issues/pregnancy/STDs/parenting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(A) ACTIVITIES OF DAILY LIVING

1. Self care/meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Independent travel/mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Trips/overnight stays away from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Parent/carer's transition programme

Name of parent: _____

Name of patient: _____

Date: Review (1) Review (2) Review (3) _____

Internet access: YES/NO _____



This transition plan is designed to help parents and carers feel confident about their knowledge and skills during the period of transition. Over the next few years we aim to equip your son/daughter and you with the necessary skills to manage their condition and hopefully increase your confidence and that of your son/daughter to transfer to adult services

Knowledge and skills

	Yes	No	N/A
I understand the meaning of transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know who's in the team and their respective roles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know about resources that offer support for parents/carers of young people with my son/daughter's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand what is likely to happen in the future regarding my son/daughter's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand the changes (physical and emotional) which occur during adolescence and how their condition potentially affects and is affected by this development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident my son/daughter is knowledgeable about their condition and its therapy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I encourage my child to regularly exercise. I am aware of any restrictions my son/daughter may have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel confident in teaching my son/daughter to become responsible for their own medication at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Parent/carers transition programme

Encouraging independence

	Yes	No	N/A
Is your son/daughter independent at home - dressing, bathing, preparing meals, doing chores, etc?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel confident for my son/daughter to be seen on their own in clinic for part or all of clinic visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand my son/daughter's rights to information, privacy and confidentiality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to advise my son/daughter about financial help and other support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Healthy lifestyle

I understand the importance of an appropriate healthy diet for young people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand the effect of smoking, drugs and/or alcohol on my son/daughter's condition and general health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to access reliable sexual health information for young people and their parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Preparation for adult services

I feel confident in teaching my son/daughter how to contact the hospital themselves and to organise their repeat prescriptions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand the differences between paediatric and adult medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the plan for my son/daughter's medical care when he/she is an adult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please list any other things you have concerns about or would like extra help/advice with:

Thank you

The Ready Steady Go materials were developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42. Users are permitted to use 'Ready Steady Go' and 'Hello to adult services' materials in their original format purely for non-commercial purposes. No modifications or changes of any kind are allowed without permission of University Hospital Southampton NHS Foundation Trust.

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