Ready Steady Go:

Moving on up together 16+ pathway

What is the 16+ moving on up together pathway?

The Ready Steady GO programme is a holistic program that equips patients with the knowledge and skill to manage their condition in children's services and transition to adult services. The moving on up program brings together the Ready questionnaire, Steady questionnaire and GO questionnaire under an aligned framework to improve transition to adult services.

The 16+ pathway applies to young persons aged 16-18 with long term conditions and aims to improve transition for patients to adult services. When a young person turns 16, they are going to be moving to adult services in the next 2 years. Before this pathway was mapped, sub-specialities in paediatrics had different rules to manage a young person's transition. This pathway aims to uniform the pathway across sub-specialities to have consensus across Trust.

During this transition, there is a decision to be made around where the young person's care will go, for example back to the GP or to an adult service. This is an important process to take a Shared Decision Making approach.

What is shared decision making?

Shared decision making is an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them. Shared decision making respects patient autonomy and promotes patient engagement. Patients who feel more involved in their decision:

- Have fewer regrets about decisions
- Report better relationships with clinicians
- Report a better experience including more satisfaction with the outcome

Specific aims of the 16+ pathway

- Improve young person and carer experience
- Provide clarity that the program is about the transition of care and not transfer of care
- Development of suitable written information for patient options are available to service users

How will we know that a change is an improvement?

A patient feedback questionnaire, named SDMQ9 +1 (appendix 5)will be used to measure improvement as a result of implanting the pathway. SDMQ9 +1 will give patients and carers the opportunity to reflect on how involved they felt in decisions made around their care. In light of the 16+ pathway, patients will be reflecting on how involved they felt in the decisions around the transition to adult services. Initially, a link to this survey will be provided with electronic communications to patients. SDMQ9 +1 improves transition for patients aged 16-18 by:

- Providing patient empowerment
- Improving shared decision making
- Providing feedback to clinicians so that they can improve and up skill
- Highlight SDM training needs for clinicians

What change can we make that will result in improvement?

The **Young Person (YP) transition flow chart** (appendix 1) has been created as a simple tool for clinical teams to follow when preparing for a YP's transition out of paediatric services. It begins when a YP turns 16 and guides them through their transition to adult services to make a final decision on where care is transferred to.

Importantly, this pathway factors in Was Not Brought (WNB) or Did Not Attend (DNA). The pathway ensures WNB and DNAs are recognised and discussed between paediatric and adult partners to agree a plan of action.

The young person should be engaged with shared decision making from the start, using **Ask 3 Questions** (A3Q) (appendix 2). Patients are encouraged to ask:

- What are my choices?
- What is good and bad about each choice?
- How do I get support to make a decision that is right for me?

Equipping patients with these questions early on in their transition process engages them in Shared Decision Making right from the start by *introducing choice*. It also helps the clinician and YP build a good relationship in the clinical encounter from the outset.

Using A3Q is particularly important in the first step of the process: deciding whether the YP needs on going consultancy support post 18. A3Q enables this to be a collaborative process through which a clinician supports the YP to make a decision about their transition. This initial conversation should bring together the clinician's expertise and what the patient knows best (their preferences, personal circumstances, goals and beliefs).

On this pathway, the YP will be asked to complete the '**Go' questionnaire** (appendix 3), the final questionnaire from 'Ready Steady Go'. The 'Go' questionnaire is also available in easy read audio version and is available through the patients e-record- 'My Medical Record' (MyMR).

The 'Go' questionnaire aims to identify any areas that need to be addressed before leaving paediatric care to ensure the YP is empowered to manage their condition. The 'Go' questionnaire improves transition for patients aged 16-18 by:

- Supporting patient empowerment
- Boosting patient confidence
- Improve shared decision making conversation

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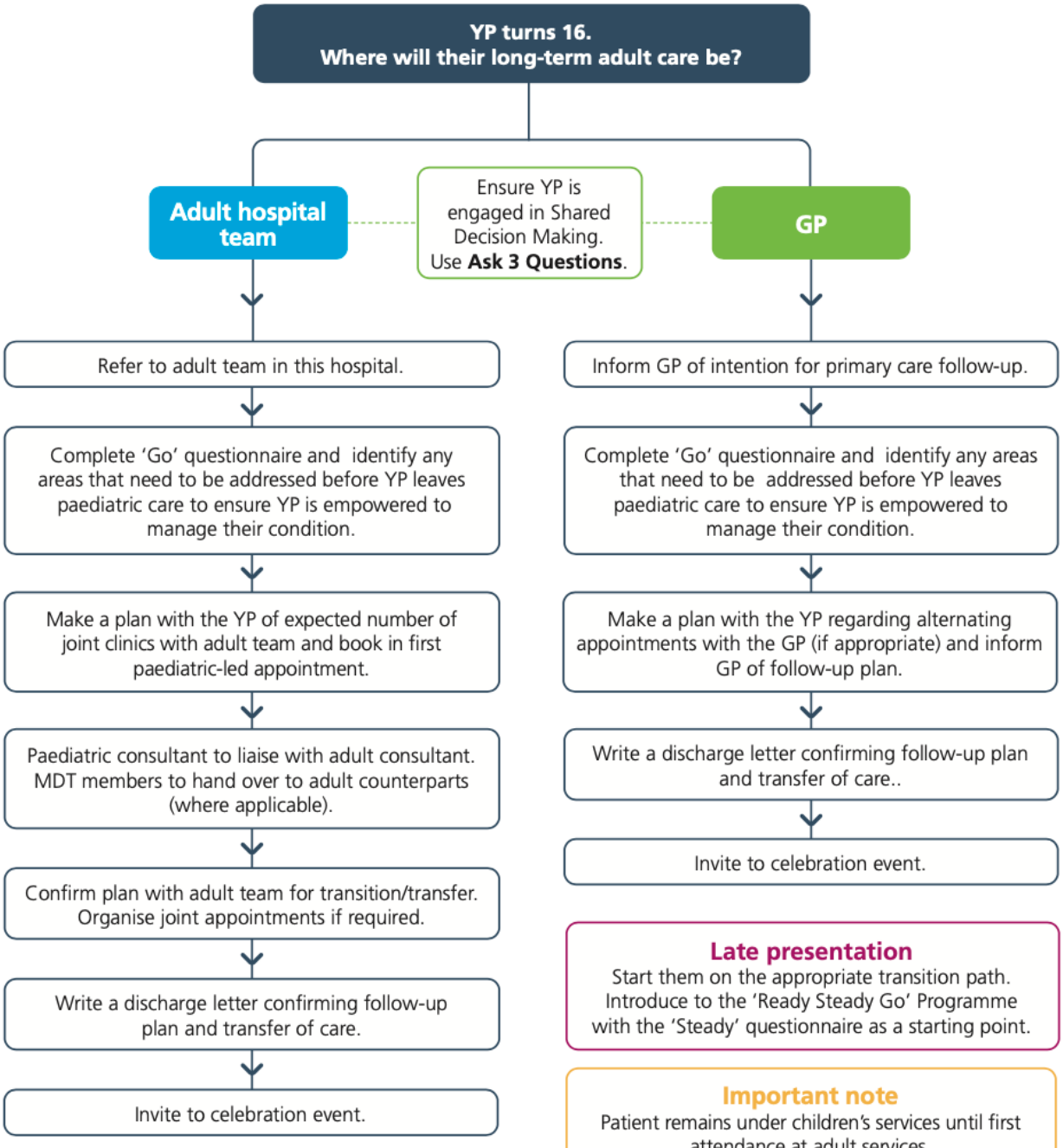
A '**Young Person (YP) Transfer of Care Checklist**' (appendix 4) has been designed to use as a prompt for the clinician to complete when the patient turns 16 and the transition hand-over begins. The proforma documents the decisions made during the pathway, by clinician and patient, around the YP's transfer of care. The proforma also documents whether A3Q was used during the decision making and that SDMQ9 +1 was used to follow up discussions for patient reflection.



Late presentation

Start them on the appropriate transition path. Introduce to the 'Ready Steady Go' Programme with the 'Steady' questionnaire as a starting point.

Important note

Patient remains under children's services until first attendance at adult services.

Ensure any missed appointments (WNB or DNA) during this transition process are recognised and discussed between paediatric and adult partners to agree a plan of action.

Transfer may be delayed if replacement appointments are considered necessary to provide thorough handover.

If a patient DNA's repeatedly in initial year of transfer, liaison with Paediatric Team is recommended to agree next steps.

Appendix 2- Ask 3 Questions poster/postcard

NHS

Ask 3 Questions

There may be choices to make about your healthcare.
Make sure you get the answers to these three questions:*

What are my choices?

What is good and bad about each choice?

How do I get support to help me make a decision that is right for me?

Your healthcare team needs you to tell them what is important to you.

It's about shared decision making.

AQuA

*Ask 3 Questions has been adapted with kind permission from the MAGIC programme, supported by the Health Foundation. Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient education and Counselling, 2011;84: 379-85

Appendix 3 – 'Go' questionnaire from Ready, Steady GO

NHS

The Ready Steady Go transition programme - Go

The medical and nursing team aim to support you as you get older 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 risks of drugs, alcohol and smoking on my condition and general health			
I understand what appropriate eating means for my general health			
I know where and how I can access reliable information about sexual health			
I understand the implications of my condition and medications 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 www.uhs.nhs.uk/Media/UHS-website-2019/Patientinformation/Childhealth/ReadySteadyGo/Printready/Ready-Steady-Go-postcard-print-ready.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)			
EDUCATION/WORK AND 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/college/work			
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 know where I can get help to deal with my emotions if needed			
I am comfortable with the way I look			
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 have all of the information I need about the adult team who will be looking after me			

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

Thank you

The Ready Steady Go materials were developed by the Transition Steering Group led by Dr Arvind Negre, 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 Pacne. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Pacne MC, Wigle M, Seewyc E. The CIN 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.

The following acknowledgement statement must be included in all publications which make reference to the use of these materials: "Ready Steady Go' and 'Hello to adult services' developed by the Transition Steering Group led by Dr Arvind Negre, 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 Pacne. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Pacne MC, Wigle M, Seewyc E. The CIN 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." Further information can be found at www.uhs.nhs.uk/readysteadygo April 2020. 2518

Appendix 4

Moving on up together: 16+ pathway

young person transfer of care discussion record

Patient details			
Forename(s)		Surname	
Patient number		Date of birth	
Does young person have a hospital passport? ☐			

Use **Ask 3 Questions** to ensure the YP is engaged in the shared decision making process

- What are my choices?
- What is good and bad about each choice?
- Who can help me make the right decision for me?

Transfer care to:		
GP ☐	Adult department same hospital/centre ☐ Please specify location:	Adult department (different hospital/centre) ☐ Please specify:

Details of plan (if applicable)					
Please add any details of specific plans for this patient within their transfer of care to adult services: *(e.g. emergency plans, specific equipment requirements etc.)*					
Any other comments:					
If transferring to adult services number of joint clinics suggested	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Booked – add in names where applicable		Date	Date	Date	Date
Location of clinic					
Attended		Y ☐ N ☐	Y ☐ N ☐	Y ☐ N ☐	Y ☐ N ☐
Anticipated date of transfer					

Processes completed		
Letter for information/referral	☐	Date
Final transfer letter	☐	Date
Ask 3 Questions used in discussion (shared decision making)	☐	Date
Sent to patient: SDM-Q9+1 feedback form	☐	Date

Appendix 5

Making a decision together

Shared decision making questionnaire (SDM Q9+1)

Name:_____ Age:____ Date:_____

Are you the: ☐ Patient ☐ Parent/carer of patient

Hospital number or date of birth (if known):_____

Please answer the questions below.

	Yes	No	Not sure
My healthcare team said we need to make a decision.			
My healthcare team said I should be involved in making the decision.			
My healthcare team told me about the different choices.			
My healthcare team explained what was good and bad about the choices.			
My healthcare team helped me understand the information.			

Shared decision making questionnaire (SDM Q9+1)

	Yes	No	Not sure
My healthcare team asked me about which choice I liked.			
My healthcare team and I discussed the different choices.			
My healthcare team and I made a decision together.			
My healthcare team and I made a plan about the decision.			
The information was useful.			

Please add anything else you would like to tell us here:

_____

_____

_____

_____

foundation for people with learning disabilities