South Wales and South West Congenital Heart Disease Network

Lost to Follow-up rates

Clinical Governance March 2019

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Standard Transition section

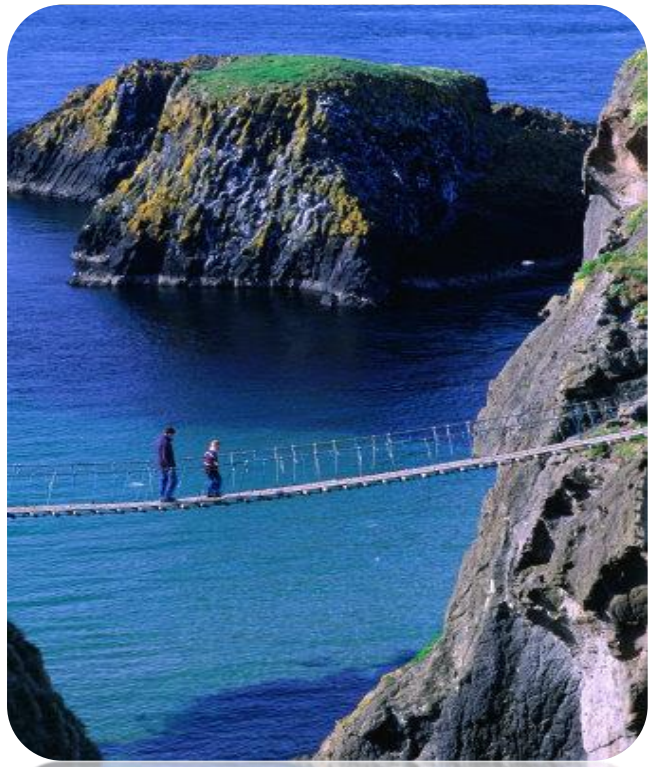
Standard	Adult	Implementation timescale
I1(L1)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year

Standard	Adult	Implementation timescale
I1(L2)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year

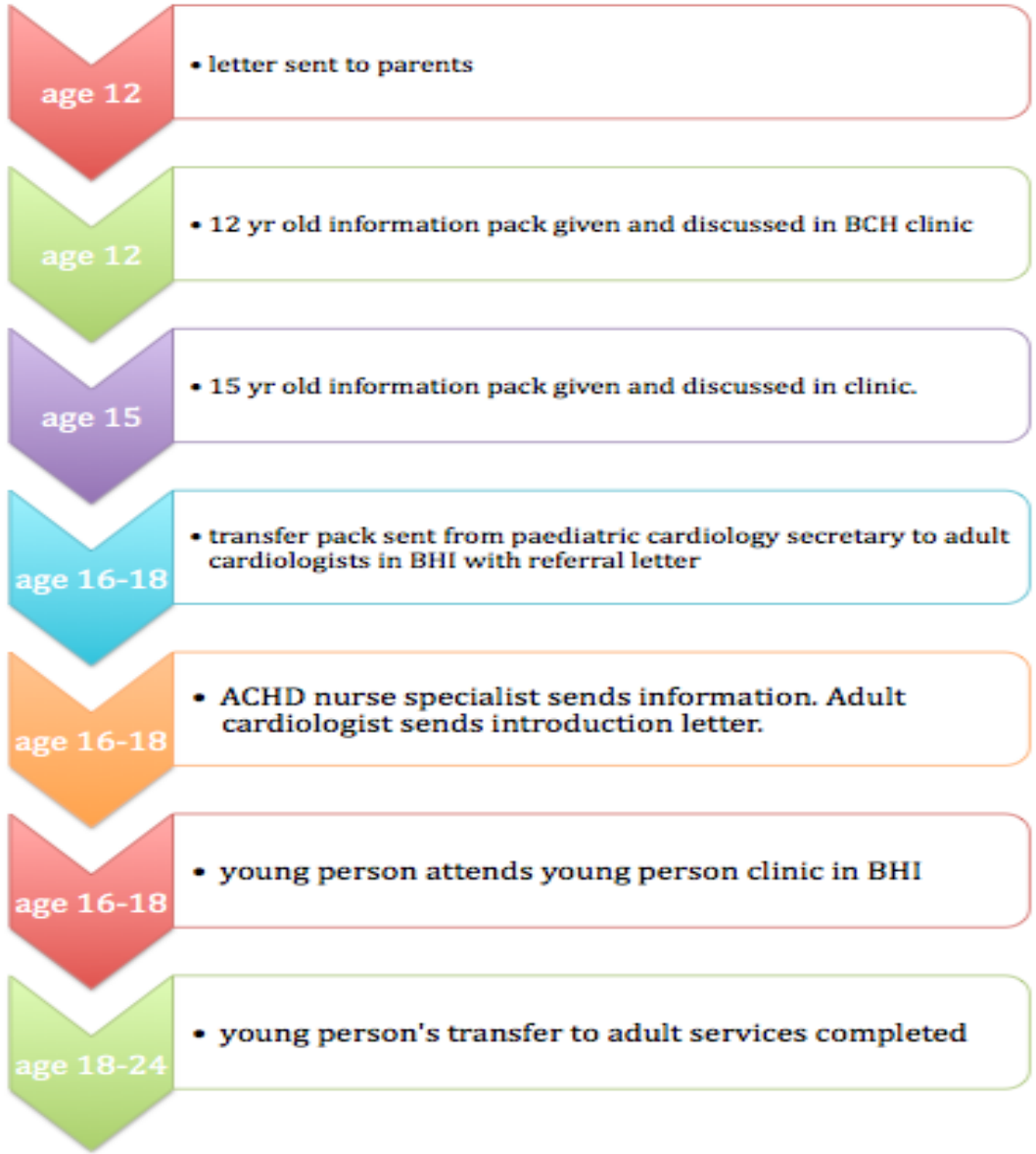
Transition and Transfer

- Transition is an **active process** that considers medical, psychosocial and educational needs of adolescents as they move from child centred to adult centred healthcare and systems. (13yrs)

- Transfer is an **event** which happens on one occasion when information or people move from one place to another.



Robertson L 2006 Shaw K L 2004
Blum RW 1993


age 12
• letter sent to parents
age 12
• 12 yr old information pack given and discussed in BCH clinic
age 15
• 15 yr old information pack given and discussed in clinic.
age 16-18
• transfer pack sent from paediatric cardiology secretary to adult cardiologists in BHI with referral letter
age 16-18
• ACHD nurse specialist sends information. Adult cardiologist sends introduction letter.
age 16-18
• young person attends young person clinic in BHI
age 18-24
• young person's transfer to adult services completed

What is the problem?

- Young people are discharged from BRHC
- We do not know if they ALL arrive in adult services
- They may be referred to a peripheral clinic after their last BRHC appointment
- They may be discharged, although unlikely
- Paper outcome BRHC, *I am referring the patient to another consultant in this Trust.*
- Paper referral letter
- No electronic outcome so difficult to audit.
- Patients transferred from Consultant to PEC or Cardiologist with an interest in the LEVEL £ clinic

Story so far…..

2007 ACHD CNS copied into paediatric Cardiology referrals from BRHC

2008 YP clinics in BHI

2010 Peripheral YP clinics

Annual YP evening

2018 commenced BRHC

Adolescent training modules x 5

Now in a better position to monitor lost to follow-up with Medway

What we currently know?

Year	Number of YP letters
2007	98
2008	107
2009	138
2010	183
2011	101
2012	79
2011	Info lost
2014	168
2015	215
2016	164
2017	157
2018	?

What we don’t know?

- If ALL young people transfer letters are copied to CNS team ? Registrar letters

- If ALL young people are transferred to BHI
- OR some to see their consultant in the peripheral clinics
- How many are discharged, paper outcome.

Why is it important?

- Poorly planned transition is associated non-adherence to treatment
- Loss to follow-up, 36% symptomatic
- Measurable adverse consequences morbidity and mortality
- Poor social and educational outcomes
- Increased admission to A and E

NSF 2006

What are the reasons young people are lost to follow-up?

Young people are lost to follow up for a number of reasons

- They do not receive their adult appointment
- They do not know where to attend for their adult appointment
- They are scared to come
- They are afraid of bad news
- They feel well
- They do not know where to come or who to contact
- Patients must acquire appropriate beliefs about adult care well before transfer.

Reid G J et al 2004, Wacker A et al 2005, Iverson K 2007 Gurvitz M Z et al 2007, Yeung E 2008, Moons P et al 2008

What action is required?

- Planned audit of ALL BRHC discharges
- Education around issues on why people are lost to follow up
- New patients seen in BHI
- Current data unclear

Comments?

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Thank you & Questions

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