

Appendix D Expert testimony papers

Expert witness 1 – Peter Winocour

Section A: NCCSC to complete	
Name:	Peter Winocour
Job title:	Consultant Physician (diabetes and endocrinology), East and North Hertfordshire NHS Trust
Address:	East and North Hertfordshire NHS Trust, Lister Hospital, Coreys Mill Lane, Stevenage, SG1 4AB
Guidance title:	Transition from children's to adult services for young people using health or social care services
Committee:	Transition from children's to adult services guideline development group
Subject of expert testimony:	Leading adult clinician in diabetes who is involved in national initiatives and is aware of the breadth of practice in implementing transition across the UK.
Evidence gaps or uncertainties:	<p>From our bibliographic database search we found more than 3000 entries of on-topic expert opinions or research (primary or secondary), but most of these do not address our specific guideline questions. For our questions on effectiveness of service models or interventions, we found four systematic reviews, but there appears to be few good quality studies on transition. In particular, there is a lack of studies which compare one type of transition planning or support with another, and so we do not have evidence to support the implementation of particular approaches for particular outcomes. Our findings concur with those of the forthcoming Cochrane review on this topic so we feel confident that we have not missed any important studies.</p> <p>Diabetes has, however, emerged as an area where there has been more practice and research interest in transition, leading to pockets of good practice across the UK. For example, our search threw up several conference abstracts drawing on service audits and pilots.</p> <p>We are aware of your long-standing practice activity in this field and would welcome your expert witness in regards to three of our questions listed below.</p>
	<p>What is the effectiveness of support models and frameworks to improve transition from children's to adult services?</p> <p>What is the effectiveness of interventions designed to improve transition from children's to adult services?</p>

The objective of these questions is to assess the effectiveness of planned transition interventions or programmes designed to improve transition from children's to adult services, including training of practitioners, and implemented in children's, adolescent and/or adult services. This includes interventions for parents to support their young adult child.

The outcomes we are interested in are condition-specific outcomes, quality of life, young people's self-efficacy and carers' outcomes. So far the reviews and the individual studies we have reviewed cover a very wide range of conditions, outcomes and interventions and so it is difficult to synthesise this into a specific set of recommendations.

Are you aware of local initiatives which have proved to be successful on the ground? And if so, what were the essential components of these that enabled their implementation, and also their uptake amongst patients?

What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services?

This question recognises that there appears to be much consensus on what ought to happen but often a lack of practice following on from that. The objective for this question is to assess the research on what hinders implementation, and what works to enhance uptake and implementation of transition guidelines.

How can adult services support effective transition for young people in transition?

The objective of this question is to identify how adult services can be more involved in the transition from children's services, and how changes can be made to make adult services more young people friendly: before transition, in transition and post transition.

Section B: Expert to complete

Summary testimony:

[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

Within diabetes transition clinics (joint between paediatrics and adult services) adherence to the principles outlined in NHS Diabetes Transition document in 2013 (Ref 1) has led to adherence to treatment and care process measures, improved levels of HbA1c, reduced non attendances at clinic and emergency hospital admissions, and qualitative measures of self-efficacy in reports from several services that have examined transition, in comparison to baseline, as well as from evidence from the national peer review of CYP services (Ref 2) .

There is unlikely to be a randomised trial of different support models, and in reality little basis for such an approach. The NHS DM working group agreed that there was no merit in a -1 size fits all approach to transition and transfer. However a dedicated young adult clinic from the age of 19-21 or to 25-30 was considered necessary and is often not provided in many adult services. The key principle of transition of diabetes care being a process over time with supported joint input from paediatric and adult services rather than consultation on at most 1-2 occasions appears key to best prospect of handover.

Recommendations and principles for best transition care of diabetes were produced by NHS Diabetes in 2013 and complement the generic recommendations using the traffic light 'Ready Steady Go' system (Reference 3) that both encapsulate the principles of a continuum of care over time in the transition setting.

Factors supporting best care through the work of the regional CYP diabetes networks include single integrated managed diabetes database information system, access to the full MDT in the transition service through use of the best practice tariff, effective in patient diabetes services to ensure care of transition cases admitted under adult services and flexible outreach clinical engagement using open non-judgemental questions and patient focused priorities covered through consultations.

Local initiatives that have been successful have been introduced in EN Herts., Northumbria, Yeovil, Portsmouth, Newham, Nottingham, Southwark and Belfast.

Innovations include a linked transition service to University health services, and enhanced education of primary care teams, particularly around earlier diagnosis of diabetes. A non-traditional model of care involving youth workers and preliminary data analysis from Newham where diabetes nurses utilising telehealth communication including Skype and text messaging has been piloted have shown better adherence to care planning, reduced emergency admissions and lower measures of HbA1c.

Full resourced MDT team appears critical to implementation of best practice standards and a named nurse supporting both transition care and transfer of any individual patient. Local audits have shown that whilst transition services operate to offer good care with the BpT standards applied the major pressure point is after or at the time of transfer to adult services where audits have shown the fall off in accessing specialist care can be as high as 25-35%. There is anecdotal evidence that flexibility not rigidity in transfer to young adult services helps the process.

Given the high prevalence of 19-25 yr old diabetes patients and the fact that many young patients present at this age without prior paediatric input the major challenge remains the care of this so called 'lost tribe'. The MDT supporting best practice tariff ceases at the age of 19 and psychology support as well as the staff patient ratio and available clinical slots ceases in the vast majority of services from the age of 19 onwards (Ref 4). There has been a recent survey confirming a major challenge in the access to training even amongst specialist medical staff in transitional care of diabetes (Ref 5)

Young adult care requires the same level of commitment from adult diabetes services (and the same resources) as those made available to the transition services. The semantics of this issue are important – transition often refers to the process of joint care – although there is significant variation in how joint services operate (transfer may be at age of 19-21 or beyond) the major challenge is in the care of those aged > 19 at transfer.

Most ambulatory outpatient services have a discharge policy and clinic services that are inflexible for adults aged over 19 and without the outreach out of hospital-primary care settings that have been suggested to improve care and contact of young adults.

All adult services should have at least 1 lead consultant and DSN to support transition and ensure continuity in a young adult service after transfer.

References (if applicable):

1. **Diabetes transition.** Assessment of current best practice and development of a future work programme to improve transition processes for young people with diabetes. NHS Diabetes 2012
2. National Children and Young People's Diabetes Peer Review Programme. Measures for Children and Young People's Diabetes 2014
3. Ready Steady Go Documentation 2014. Accessed at: www.uhs.nhs.uk/readysteadygo
4. Care of adolescents and young adults with diabetes - much more than transitional care – a personal view. Winocour PH. Clinical Medicine 2014; 14:3:1-5
5. **Training Needs in Adolescent & Young Adult Health and Transition in Paediatric and Adult Higher Specialist Trainees in Endocrinology & Diabetes in the UK.** RJ Wright, S Chapman, K Cheer, REJ Besser, CA Steele, S Sankar, P Dimitri, P Winocour, H Gleeson , on behalf of the Young Adult and Adolescent Special Interest Group . Submitted for publication 2015

Expert witness 2 – Janet McDonagh

Section A: NCCSC to complete	
Name:	Janet McDonagh
Job title:	Senior Lecturer in Paediatric and Adolescent Rheumatology
Address:	Centre for Musculoskeletal Research, Institute for Inflammation and Repair, The University of Manchester, Second floor Stopford Building Oxford Road Manchester M13 9PT
Guidance title:	Transition from children's to adult services for young people using health or social care services
Committee:	Transition from children's to adult services guideline development group
Subject of expert testimony:	Transition from children's to adult health services for young people with long-term conditions or disabilities: Effectiveness of service models or interventions.
Evidence gaps or uncertainties:	<p>From our bibliographic database search we found more than 3000 entries of on-topic expert opinions or research (primary or secondary), but most of these do not address our specific guideline questions. For our questions on effectiveness of service models or interventions, we found four systematic reviews, but there appears to be few good quality studies on transition. In particular, there is a lack of studies which compare one type of transition planning or support with another, and so we do not have evidence to support the implementation of particular approaches for particular outcomes.</p> <p>We are aware of your long-standing research activity in this field, and will indeed be including some of your papers in our evidence base. One of your studies was excluded on the basis of study design criteria (McDonagh et al 2007), however, this was otherwise a well-conducted study and in light of all your other research in this field we would welcome your expert witness in regards to three of our questions listed below.</p>
<p>What is the effectiveness of support models and frameworks to improve transition from children's to adult services?</p> <p>What is the effectiveness of interventions designed to improve transition from children's to adult services?</p> <p>The objective of these questions is to assess the effectiveness of planned transition interventions or programmes designed to improve transition from children's to adult services, including training of practitioners, and implemented in children's, adolescent and/or adult services. This includes interventions for parents to support their young</p>	

adult child.

The outcomes we are interested in are condition-specific outcomes, quality of life, young people's self-efficacy and carers' outcomes.

So far the reviews and the individual studies we have reviewed cover a very wide range of conditions, outcomes and interventions and so it is difficult to synthesise this into a specific set of recommendations. We are interested in approaches that appear to be generalizable across conditions, but also which we can provide detailed information on to facilitate uptake of recommendations.

What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services?

This question recognises that there appears to be much consensus on what ought to happen but often a lack of practice following on from that. The objective for this question is to assess the research on what hinders implementation, and what works to enhance uptake and implementation of transition guidelines.

How can adult services support effective transition for young people in transition?

The objective of this question is to identify how adult services can be more involved in the transition from children's services, and how changes can be made to make adult services more young people friendly: before transition, in transition and post transition.

Considering your breadth and length of research activity, we were hoping you might provide insight from both a research and practitioner perspective, as well as drawing on the findings from your studies which have researched the impact of implementing good practice guidelines in the UK. Are there differences in outcomes observed within clinics as well as in the research studies? How do your study findings and practice experiences speak to these three questions related to purposeful and planned transition from children's to adult health services?

Section B: Expert to complete

Summary testimony:

[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

Q1. There already exist effective transitional care support models and frameworks developed by committed and enthusiastic health professionals within NHS practice but these are patchy and the majority are condition specific in terms of delivery and/or funding sources. As they are condition-specific, transitional care of young people with complex multisystem disease remains challenging as the young people "belong" to several services/specialties.

Models and frameworks to improve health transition for young people should be developmentally appropriate, and be underpinned by the core frameworks of adolescent health – namely biopsychosocial development and resilience. If a developmentally appropriate life course approach is adopted, then transitions will be addressed by definition whether it be health, education and /or social transitions. However it is not always clear in both clinical practice as well as in research reports, as to the developmentally appropriateness of either the programmes that currently exist or the broader context (institution, network etc.) they exist within.

The current literature for transitional care is frustrated by inconsistencies in definition – particularly between transfer and transition. It is not always clear what is meant by a “transition clinic” or, “transition programme” [Shaw 2014]. For example, some are an annual single-visit handover clinic involving both paediatric and adult teams with no prior preparation nor attention to the influences of ongoing brain development into the third decade of life.

Crowley et al (2011) reported that dedicated clinics were associated with success but whereas 3 of 8 so-called combined clinics were successful, 3 of 4 young adult clinics were similarly successful. One could argue that the latter are more developmentally appropriate, as they attend to the particular developmental needs of late adolescence and emerging adulthood.

The potential of a transitional care coordinator is obvious from the complex nature of health transition and the potential has been recognised in the literature for a long time [Betz 2005; Crowley 2011]. However it continues to be under-recognised in many who already undertake this role [Shaw 2014]. It is important to state that this does not necessarily have to be a nurse or other health professional and may be a youth worker or indeed a more basic health navigator role [van Wallegghem 2008]. To have a chance of success, transitional care needs to be seen as integral to all services seeing children with long term conditions and not a luxury add-on which is the first to go when resources are limited.

As mentioned above, transitional care needs to be underpinned by the adolescent health frameworks including that of resilience. A key aspect of this is a knowledge and skills framework, another aspect recognised by Crowley et al (2011) in their review of successful programmes. The nature of such “curricula” for young people and their families is not always clear particularly as to whether they extend beyond the disease and include generic skills of communication, decision-making, negotiation, autonomy etc. Such skills however need to be also considered in context i.e. are the services they will access, conducive to fostering positive adolescent development. It is therefore important to consider whether transitional care services are young person friendly e.g. compliant with You’re Welcome quality criteria [Hargreaves 2011]. The evidence base supporting this area is important to consider [Ambresin 2013] when reviewing the literature for transitional care as young people with long term conditions are young people are first and foremost.

Similarly such skills training for young people needs to be matched by similar skills training for parents who can then enable the young person to practice such skills in the social context of the extended family. The classical paternalistic /family centred approach of paediatrics (and the training of professionals in these settings) does not always recognise the gradually evolving autonomy of the young person and the impact this has on parenting. Likewise, adult services need to acknowledge that these processes are still continuing post-transfer and need similar support to ensure success.

One needs to consider both success of transitional care programmes as well as sustainability [Price]. Factors determining sustainability include committed teams rather than individuals, funding, institutional support and recognition, effective succession planning of key individuals etc.

Continuity is an important aspect of transitional care whether it be informational continuity or relational continuity or any of the other continuities described as important in the literature [Allen 2012]. Continuity relates to coordination and provider

characteristics. Enhanced follow-up was identified as potentially important by Crowley et al 2011 and it can be argued that, just as the therapeutic alliances established in the years spent in paediatrics are important, so are those in adult care. However it will take time for these to become established particularly in view of the multiple transitions occurring in late adolescence. Time between last paediatric appointment and first adult appointment may therefore be a potential important quality indicator. Likewise, the attendance at the first few adult clinic appointments is another potential indicator.

No model will fit all e.g. rare disease “feeder paediatric service” transferring to single regional /national adult clinic e.g. cystic fibrosis vs the more common disease paediatric services transferring to multiple adult clinics e.g. juvenile idiopathic arthritis. Although it is the ideal for young people to meet the adult team prior to transfer, this may not be feasible if the paediatric service transfers to multiple adult teams across a wide geographical area. But alternatives to this include overlap visits when the young person returns to the paediatric service after their first visit to the adult service and/or a period of shared care. Clarity of responsibility however is vital for success of the latter arrangements.

Having worked as a clinical researcher in this field for 15 years I personally would advocate that we move away from transition terminology and rather consider developmentally appropriate care for adolescents and young adults in paediatric and in adult care. In so doing we will ensure the integration of adolescent health principles and the recent neuroscience advances in the understanding of adolescent brain development, into the routine care of such young people in both paediatric and adult services. These principles by definition recognise the key transitions at this fascinating stage of the life course. One could therefore surmise that as child-centred services become more adolescent-centred and the receiving adult services, more young adult friendly, then the gap between the services, so often acutely felt by young people and their families, will lessen in breadth and depth.

There is a large evidence base in the qualitative literature of what young people and their families want and need [Lugasi 2011] and this does not differ significantly between conditions. There are therefore significant potential of efficiencies of scale when considering transitional care interventions within the NHS. Most interventions currently delivered in the NHS today are very similar in content, reflecting the generic nature of transition. However most interventions to date remain condition or specialty –specific in terms of delivery and/or funding. Of interest, the transition readiness tools developed a decade ago in the evidence based rheumatology transition programme [McDonagh 2006] have been recently adopted generically with minimal change of the original by the Southampton “Ready Steady Go” programme. There are now even shorter questionnaires being developed which may be similarly useful across specialties e.g. Transition Q (Klassen 2015).

Q2. The IDAHO (Implementing Developmentally Appropriate Healthcare for Young people Across Organisations) study within the University of Newcastle NIHR Transition project will hopefully address this further as it is looking at the barriers and facilitators of implementing developmentally appropriate health care for young people across institutions.

Provider characteristics have been shown to be important determinants of adolescent satisfaction with transitional care [Shaw 2007; Sonneveld 2013], often greater than processes and/or environment. At this stage of service development, individual champions for transition remain important and should be adequately supported to progress the area further [Price 2011]. Many of the key provider characteristics can

be influenced by appropriate training. However unmet training needs of health professionals have been identified by several authors in the UK [McDonagh 2004, 2006, Hambly 2009; Sebastian 2012] and formal training opportunities remain limited.

As well as specific transitional care interventions, actual process issues need to be considered as they may also be important potential facilitators e.g. key continuities [Allen 2012], enhanced follow up [Duguépéroux 2008], adolescent friendly settings [Ambresin 2013] etc.

Q3. Many adult services already do recognise the importance of young adult services [Harden 2012]. Conversely, many paediatric services are not young person friendly! Many adult professionals involved (as in paediatrics) are unrecognised by their managers and ongoing acknowledgement that transitional care is as much an adult concern as paediatric is vital. So much of transitional care service development and research has been paediatric driven to date and engagement of the adult sector in both will be imperative for future work in this area. Joint appointments of professionals who work in both sectors as well as joint training initiatives will continue to be useful to facilitate the cross-fertilisation of expertise at the paediatric-adult interface.

References (if applicable):

Allen D, Cohen D, Hood K, Robling M, Atwell C, Lane C, Lowes L, Channon S, Gillespie D, Groves S, Harvey J, Gregory J. Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study. *J Health Serv Res Policy*. 2012 Jul;**17**(3):140-8.

Ambresin AE, Bennett K, Patton GC, Sanci LA, Sawyer SM. Assessment of youth-friendly health care: a systematic review of indicators drawn from young people's perspectives.

J Adolesc Health. 2013 Jun;**52**(6):670-81.

Betz CL, Redcay G. Dimensions of the transition service coordinator role. *J Spec Pediatr Nurs* 2005;**10**(2): 49-59.

Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between pediatric and adult healthcare: a systematic review. *Arch Dis Child*. 2011 Jun;**96**(6):548-53.

Duguépéroux I, Tamalet A, Sermet-Gaudelus I, Le Bourgeois M, Gérardin M, Desmazes-Dufeu N, Hubert D. Clinical changes of patients with cystic fibrosis during transition from pediatric to adult care. *J Adol Health* 2008; **43**: 459-465.

Hambly H, Robling M, Corwne E, Hood K, Gregory JW for the DEPICTED study team. Communication skills of healthcare professionals in paediatric diabetes services. *Diabetic Medicine* 2009;**26**:502-509.

Hargreaves DS. Revised You're Welcome Criteria and Future Developments in Adolescent Healthcare. *J Clin Res Pediatr Endocrinol*. 2011 Jun;**3**(2):43-50.

Harden PN, Walsh G, Bandler N, Bradley S, Lonsdale D, Taylor J, Marks SD. Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. *B Med J* 2012: 344: e3718.

Hilderson D, Westhovens R, Wouters C, Van der Elst K, Goossens E, Moons P.

Rationale, design and baseline data of a mixed methods study examining the clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: the DON'T RETARD project. *BMJ Open*. 2013 Dec 2;3(12):e003591. doi: 10.1136/bmjopen-2013-003591.

Klassen AF, Grant C, Barr R, Brill H, Kraus de Camargo O, Ronen GM, Samaan MC, Mondal T, Cano SJ, Schlatman A, Tsangaris E, Athale U, Wickert N, Gorter JW. Development and validation of a generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions: the TRANSITION-Q. *Child Care Health Dev*. 2014 Oct 28. doi: 10.1111/cch.12207. [Epub ahead of print].

Lugasi T, Achille M, Stevenson M. Patients' perspective on factors that facilitate transition from child-centred to adult-centred health care: a theory integrated metasummary of quantitative and qualitative studies. *J Adol Health* 2011;**48**:429-440.

McDonagh JE, Minnaar G, Kelly KM, OConnor D, Shaw KL. Unmet education and training needs in adolescent health of health professionals in a UK Children's Hospital. *Acta Paediatr* 2006 ; 95(6): 715-9.

McDonagh JE, Southwood TR Shaw KL. Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology (Oxford)* 2004;**43** (6): 737-743.

McDonagh JE, Southwood TR, Shaw KL. Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *J Child Health Care* 2006;**10**(1):22-42.

Price C, Corbett S, Dovey-Pearce G. Barriers and facilitators to implementing a transition pathway for adolescents with diabetes: a health professionals perspective. *Int J Child Adol Health* 2011;**3**(4):489-498.

Shaw KL, Watanabe A, Rankin E, McDonagh JE. Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. *Child Care Health Dev*. 2014 Sep;**40**(5):663-70.

Shaw KL, Southwood TR, McDonagh JE. Young People's satisfaction of transitional care in adolescent rheumatology in the UK. *Child: Care, Health & Development* 2007;**33**(4):368-79.

Sonneveld HM, Strating MM, van Staa AL, Nieboer AP. Gaps in transitional care: what are the perceptions of adolescents, parents and providers? *Child Care Health Dev*. 2013;**39**(1):69-80.

Sebastian S, Jenkins H, McCartney S, Ahmad T, Arnott I, Croft N, Russell R, Lindsay JO. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: Differing perceptions from a survey of adult and paediatric gastroenterologists. *J Crohns Colitis*. 2012;**6**(8):830-44.

Van Wallegghem N, MacDonald CA, Dean HJ. Evaluation of a systems navigator model for transition from paediatric to adult care for young adults with type 1 diabetes. *Diabetes Care* 2008; **31**:1529-1530.

Expert witness 3 – Julie Pointer

Section A: NCCSC to complete

Name:	Julie Pointer
Job title:	Transition Development Manager, Surrey Short Breaks for Disabled Children Preparing for Adulthood Regional Lead
Address:	Website: http://www.preparingforadulthood.org.uk/
Guidance title:	Transition from children's to adult services for young people using health or social care services
Committee:	Transition from children's to adult services guideline development group
Subject of expert testimony:	Preparing young people for a positive transition to adult life.
Evidence gaps or uncertainties:	<p>From our bibliographic database search we found more than 3000 entries of on-topic expert opinions or research (primary or secondary), but most of these do not address our questions and we have found few good quality evaluations. Those studies we have found explore areas of unmet need, and describe elements of good practice. We would like to go beyond broad descriptions and consider in more detail examples of when transition was well managed for young people with disabilities, including those with mild disabilities who may not qualify for adult services. We also have a question on how to implement best practice guidelines in this area.</p> <p>So we are asking for your witness in regards to three of our questions, which we feel are closely linked together.</p>
<p>How can the transition process (including preparing the young person, making the transfer and supporting them after the move) best be managed effectively for those receiving a combination of different services?</p> <p>For this question we are particularly interested in how transition planning can be co-ordinated and planned across different services, in particular in terms of the link between health and social care and the role of education.</p> <p>We have found six studies that in some way address this question, including work by the Social Policy Research Unit in York. However, we have not found any good quality evaluations of specific models, and nothing about education- either mainstream or SEND models. Considering the recent changes in this area following the Children and Families Act 2014, and the Care Act 2014, research is also partly out of date.</p>	
<p>What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services?</p> <p>The objective for this question is to assess the research on what hinders</p>	

implementation, and what works to enhance uptake and implementation of transition guidelines. It is our understanding that there are broad agreements on principles for good transitions but that these are not reflected in current UK practice. Would you know of any examples of where they have been able to implement transition guidelines and adhere to them? Why were they able to do so, when so many other areas have not?

We found two studies for this question, and while one of them is from the UK and highly relevant, we would like to know more about how to overcome barriers to implementation in this area.

How can adult services support effective transition for young people in transition?

The objective of this question is to identify how adult services can be more involved in the transition from children's services, and how changes can be made to make adult services more young people friendly: before transition, in transition and post transition.

Our search did not identify any study on adult health and social care services' role in transition. It is our understanding from the literature that adult services' threshold for referral is different to children's services that it in effect creates a 'gap' of service provision. How can this be addressed and what is the role of adult services in reducing this gap?

We are aware that education is often ongoing for young people across this gap, and we would like to know of any good practice examples where they work alongside health and social care during transition. We would be interested to know more about the implications of Education Health and Care Planning on transition planning and processes.

In addition, what is the role of adult services to provide purposeful and planned transitions for those that do meet their referral criteria? There is concern that for some young people the plan for what they will receive after transition is not implemented due to lack of commitment from adult services.

What transition training is available for health and social care practitioners in children's and adult services? What is the effectiveness of transition training?

One objective of this question is to identify the kinds of 'transition' training programmes that are available in the UK. The other objective is to identify studies which have measured the effectiveness of training. We would be interested in hearing about training that you have experienced as effective in this area, and what the most important components of such training might be.

We have found the most successful training to be around using person centred approaches for young people with SEND. Training also needs to ensure that all practitioners have a good knowledge and understanding of both children and adult legislation, including the Children and Families Act, the Care Act, the Mental Capacity Act and best interest decision making, and the health Continuing Care framework.

Section B: Expert to complete

Summary testimony:

[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

Transition planning for all young people with additional needs is best managed in a coordinated way, using a person centred approach.

The Children and Families Act, in particular the SEND reforms and the Code of Practice lays out how local areas should be working in a coordinated way, using a person centred approach to raise aspirations for young people from 0-25. The preparing for adulthood section of the code ([section 8](#)) talks about how this should happen, starting with a person centred transition review from year 9. The Code is very much focussed on outcomes for young people that support them to think about what is positive and possible for their futures.

The key life outcomes for young people with SEND are:

- Employment
- Somewhere to live
- Friends, relationships and being part of your community
- Good health

Each local area has a legal responsibility to publish a Local Offer laying out what support and services are available for young people with SEND and in particular with an emphasis on inclusion and allowing young people to lead ordinary lives.

There are a number of examples on the Preparing for Adulthood [website](#) that show where local areas have begun to work in a more coordinated way with health, education and social care coming together to improve life outcomes for young people with SEND. The Education, Health and Care Plan is an idea way to ensure young people move into adult life with a comprehensive, person centred and outcomes focused plan.

Through the initial pathfinder work, and since the Act came into force local areas are beginning to work in a much more co-designed and co-produced way, but all acknowledge that there still needs to be a big shift in culture to fully ensure that young people and their families are able to influence their own plans and have a more strategic role to play locally.

The work that was carried out during the pathfinder to test out possible new ways of working is also captured and can be viewed [here](#)

There needs to be an opportunity to ensure that the EHCP can also become the adult support plan under the Care Act legislation for eligible young people once they turn 18. This will be a challenge given that most local areas have systems that do not work together and a segregation of children and adult services.

It is also important that local areas think about how they can use information captured in individual young people's plans to then influence their local commissioning strategy so that young people and their families are able to have the right opportunities and support that works best for them.

One way for young people and families to have support that works for them is through the use of personal budgets using Education, Health or Social Care monies or a combination of all three.

The Preparing for Adulthood team have been looking at how to scale up planning with young people and also how to ensure that information captured from plans informs the Local Offer and the local commissioning plan.

Expert witness 4 – Robert Carr

Section A: NCCSC to complete	
Name:	Robert Carr
Job title:	Consultant Haematologist
Address:	Guy's & St Thomas' Hospital Foundation Trust Westminster Bridge Road London SE1 7EH
Guidance title:	Transition from children's to adult services for young people using health or social care services
Committee:	Transition from children's to adult services guideline development group
Subject of expert testimony:	Effectiveness of planned transition interventions or programmes designed to improve transition from children's to adult services
Evidence gaps or uncertainties:	<p>From our bibliographic database search we found more than 3000 entries of on-topic expert opinions or research (primary or secondary), but most of these do not address our questions and very few studies focus on transition from CAMHS in particular. It is our understanding that there are broad agreements on principles for good transitions but that these are not reflected in current UK practice. We therefore also have a question on how to implement best practice guidelines in this area. For our questions on effectiveness of service models or interventions, we found four systematic reviews, but there appears to be few good quality studies on transition. In particular, there is a lack of studies which compare one type of transition planning or support with another, and so we do not have evidence to support the implementation of particular approaches for particular outcomes. Our findings concur with those of the forthcoming Cochrane review on this topic, as well as five other recent systematic reviews, so we feel confident that we have not missed any important studies.</p> <p>One of the models of transition is to have an intermediate phase for young people who have 'grown out of' children's care yet are not quite ready for adult services. This kind of model is of course particularly helpful for young people who are diagnosed close to the (rather artificial cut-off of children's services) age of 18.</p> <p>We are aware of your long-standing engagement in the TYA Cancer model and would welcome your expert witness in regards to the questions below.</p>
<p>What is the effectiveness of support models and frameworks to improve transition from children's to adult services?</p> <p>What is the effectiveness of interventions designed to improve transition from children's to adult services?</p> <p>The objective of these questions is to assess the effectiveness of planned transition</p>	

interventions or programmes designed to improve transition from children's to adult services, including training of practitioners, and implemented in children's, adolescent and/or adult services. This includes interventions for parents to support their young adult child. The outcomes we are interested in are condition-specific outcomes, quality of life, young people's self-efficacy and carers' outcomes.

As we say above, we have not found any substantial evidence to address these questions (prospective comparison studies), and so we would like to know how your professional knowledge of the TYA Cancer model speaks to these questions, including any audits or patient consultations that you are aware of, in regards to this specific model

We are also interested to know what the resource implications have been for the TYA Cancer model, and sources of funding.

What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services?

This question recognises that there appears to be much consensus on what ought to happen but often a lack of practice following on from that. The objective for this question is to assess the research on what hinders implementation, and what works to enhance uptake and implementation of transition guidelines.

Again, we would like to hear about your experience in terms of the implementation of the TYA cancer models, what in your experience are the challenges to implementation and what can help it?

Section B: Expert to complete

Summary testimony:

[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

Lessons from development of a young adult cancer service

The NICE Guidance on Improving Outcomes for Children and Young People with Cancer (2005) can be distilled to two fundamentals:

1. That Young People, aged 16 to 24y, should be treated for malignancy in a separate service, "not with younger children or older adults".
2. That in parallel with the treatment for their malignancy, they should be supported by a separate, but closely linked, Teenage and Young Adult (TYA) multidisciplinary team who would provide the psycho-social support so necessary at this age.

My experience of implementing this guidance at Guy's & St Thomas' NHS Trust relates to young people newly diagnosed with malignancy in the TYA age range. They are not in transition between services, but their needs are shaped by this period of transition from childhood to adult independence.

Developing the Service

Prior to initiating a specialist TYA Cancer Service in our large Regional Cancer Centre, patients within this age group were dispersed and invisible within the different tumour group services. It was thought that such patients were rare.

The TYA Cancer Service was initiated in 2009. The TYA MDT now comprises a Lead Clinician, Lead Nurse, Psychologist, Social Worker, Community Support Worker, Dietitian and Fertility Consultant. We see 65 newly diagnosed patients annually across the spectrum of malignancy. More than 200 are having on-going support. Eighteen months ago we established a multi-disciplinary clinic where all patients meet the full team, to introduce them to what we can offer, and for us to screen them for their particular needs. They are then reviewed in the clinic every 3-6 months, with one-to-one support as needed through treatment and beyond.

What we have learned

The range and complexity of psychological and social problems that a 'cancer' diagnosis creates in a South London population where many are already disadvantaged has far exceeded expectation. In addition to the expected difficulties with disrupted education and employment, and insecurity of housing, existing friendships and peer support networks frequently evaporate. The overwhelming consequence can be isolation and feelings of insecurity.

Principal areas of benefit

1. A multi-disciplinary approach. An unexpected benefit of patients seeing a variety of health professionals has been that patients often reveal different areas of concern to each member of the team. This is particularly true with regard to mental health, where standard screening tools fail to accurately identify significant levels of distress.
2. A patient community. Four years ago we established a private Facebook page to create a virtual community for peer support. From feedback, this has been the single most effective innovation, and has now been duplicated by other cancer services.
3. Providing an easy point of contact. Young patients often do not know who to contact, or are reluctant to contact their oncology team when they are worried. The lead nurse, through regular texting contact, is an easy source of advice and able to link patients into their oncology team for rapid access when needed.

Challenges

- The service we have developed provides benefit that is difficult to quantify in an environment where finance and business cases hold sway. However the patients provide many unsolicited compliments and are vocal advocates for what we do.
- All the full time posts have, of necessity, been established through charity funding.
- The tumour groups oncology teams were initially uncertain as to what the TYA MDT actually provided. The work of the Team is now highly valued.
- In the current climate, despite backing of the 2005 Guidance and demonstrable benefit, the service remains insecure. NICE should mandate multidisciplinary transition support.

A model of transition for Sickle Cell Disease in South London

Sickle Cell Disease (SCD) is a chronic multi-system disorder whose main clinical feature is long standing anaemia punctuated by episodes of acute pain. As survival

improves there is an increasing demand on adult services and the need to improve coordination of the transfer from paediatric into adult care. The demands of living with chronic illness presents additional challenges to normal adolescence development, which adds complexity to preparing for GCSEs and entering higher education, social development and gaining employment, all of which threaten quality of life. This highlights the need for seamless services that support young people with chronic illness to achieve their maximum potential in terms of education, health, development and well-being.

Developing the SCD transition at GSTT

Initiated in 2007 with charity funding for a Clinical Nurse Specialist and psychologist. These meet the young person at age 12 or 13yrs in the paediatric environment to introduce the concept of transition. The key objective is to support the young person to achieve independent self- management skills. An assessment tool has been developed (passport document) which provides a structured way to assess the knowledge gaps and present information in an age-appropriate manner, increasing understanding of their condition and its implications on their daily life, life style modifications, including medication adherence and understanding the importance of attending clinics for disease monitoring to maximise long term health outcomes. These skills are necessary for the young person to function in the adult services, enhancing the role of the 'expert patient'. This process occurs over a period between age 12 to 16/17yrs when they transfer to the adult service, progressively becoming less dependent on their parents and other adults. The program also supports parents with strategies to gently relinquish their central role and begin to empower the young person to take charge of their care.

A service evaluation of the impact on young people demonstrated:

- Increased patient confidence & independent self-management skills.
- 35% more patients remained actively engaged with the service post transition to the adult hospital.
- A strong relation between lack of engagement with the transition service and those who became lost to follow up.

Principal areas for support:

- Staff training to increase understanding and skills to engage and communicate with young people.
- Joined up working between primary and secondary care, and support from local Authorities and commissioners.
- Adjustments to services to deliver young people friendly services which are age appropriate, e.g. adolescent wards and evening/weekend clinics which allow full time attendance for education or employment without compromising medical care.

Expert witness 5 – Helen Crimlisk

Section A: NCCSC to complete

Name:	Helen Crimlisk
Job title:	Consultant Psychiatrist
Address:	Sheffield Health and Social Care Foundation Trust Fulwood House, Old Fulwood Road, Sheffield S10 3TH
Guidance title:	Transition from children's to adult services for young people using health or social care services
Committee:	Transition from children's to adult services guideline development group
Subject of expert testimony:	Transition from child and adolescent mental health services to adult mental health services
Evidence gaps or uncertainties:	<p>Transition from child and adolescent mental health to adult services:</p> <p>From our bibliographic database search we found more than 3000 entries of on-topic expert opinions or research (primary or secondary), but most of these do not address our questions and very few studies focus on transition from CAMHS in particular. You might be aware of the recent systematic review by Paul et al (2014). They found only three studies which evaluated the effectiveness of interventions or models to support purposeful and planned transition from children's to adult mental health services, and only one of which used a comparison group. In addition, we have specific questions about the role of adult services in facilitating transitions. It is our understanding that there are broad agreements on principles for good transitions but that these are not reflected in current UK practice. We therefore also have a question on how to implement best practice guidelines in this area.</p>
<p>How can adult services support effective transition for young people in transition?</p> <p>The objective of this question is to identify how adult services can be more involved in the transition from children's services, and how changes can be made to make adult services more young people friendly: before transition, in transition and post transition.</p> <p>Our search identified some academic publications about AMHS role in transition, but none of these were sufficiently reported to be included in our review. It is our understanding from the literature that adult services' threshold for referral is so different to child and adolescent mental health services that it in effect creates a 'gap' of service provision for young people not accepted into adult services but being transferred out of CAMHS. How can this be addressed and what is the role of adult services in reducing this gap? In addition, what is the role of adult services to provide purposeful and planned transitions for those that do meet their referral criteria when aging out of CAMHS?</p>	
<p>What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services?</p> <p>The objective for this question is to assess the research on what hinders implementation, and what works to enhance uptake and implementation of transition</p>	

guidelines.

We identified 4 unique records for this question, two of which appear to relate to the same service, another which is from the US and so of limited relevance to the UK context, and finally one survey of ADHD provision which mainly presents problems for implementation of guidelines rather than solutions.

Section B: Expert to complete

Summary testimony:

[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

Transition is an important phase and transition between child and adult mental health services is only one of a range of transitions going on for young people

There are many differences between AMHS and CAMHS delivery models which can be bewildering to patients, carers and also professionals – some of the most important are described below.

Most adult mental health teams operate an access / recovery model with rapid access into services for assessment /consultation and advice vs a period with the recovery team for specific mental health intervention based on need and diagnosis – (cf clusters). There is a shift in emphasis between CAMHS and AMHS moving towards episodes of care, recovery plans etc.

AMHS have a more clearly defined threshold between primary and secondary mental health care with a stepped care model in operation for many people.

AMHS have more developed crisis and home treatment teams to enable out of hospital care and treatment.

Some people who meet a threshold for social care needs may need an ongoing funded social care package to address this (the threshold is set by the La – usually substantial or critical) Some social care funding may be available for “enablement” strategies.

Local strategies we are using to address this: (Sheffield).

Joint commissioning strategy for young people with CAMHS and AMHS senior clinicians and young people present.

Transition protocol with a series of standards agreed by all (see Table 1 below). Preparation for transition seen as an important part of this (c.f. Ready steady Go programme in Southampton).

In Sheffield as a result of the partnership arrangement, social care funds a short term provision “Recovery Education Programme” – as part of this a “Transitions Group” has been set up with the needs of young people in mind with significant mental health problems. It runs for 6 weeks looking at wellness, social and peer support, -

educational /vocational opportunities, artistic and exercise related recovery strategies etc (see Transition Group below).

Transition Clinics – had been trialled but problematic as rely on a few “experts” and we need a systematic approach.

Table 1 - Transition Process

The transition process overarches pre-transition preparation in CAMHS, transition handover meeting (s) and development of age-appropriate care plan post-transition in AMHS

CAMHS	Issues	AMHS
Pre-transition preparation		Post-transition issues
Education and provision of information to YP about their condition and proposed treatment plan (Discussion with AMHs if uncertainty about care pathway)	Provision and sharing of information and planning further care	Plan to address any outstanding information gaps Review psycho-educational needs and address appropriately Consider referral to transition group
Recent review of treatment needs, risks and creation of summary of care and reasons for referral	Treatment / care needs and risks	Arrange review of care plan in line with need, review and revise as necessary and plan discharge
Plan and set up transition meeting and support young person to attend meeting with carer if appropriate	Transition meeting	Consider age specific issues required and make adjustments necessary – room, who should be present, time etc.
Discuss issue of young person’s choice with regard to carer / family involvement	Relevant carers / family involved	Respect wishes of young person with regards to carer / family involvement
Clarify with young person what their needs / requests are with regard to future care or treatment	Collaborative discussion to agree care plan	Ensure understanding and appropriate communication to young person, carers, GP and CAMHS confirming completion of transition process and plan for future

--	--	--	--

Transition Group

Moving into adulthood

Come and meet other people, learn new skills and ways to cope with your mental health condition. The group will run once a week for 10 weeks.

The group leaders and service user helpers will come each week & there will often be guest speakers

The group leaders will be happy to speak to you before & after the group & answer any questions

We will not put you on the spot or ask you to do anything you do not want to

The group will have no more than 14 members

Meet other young people

Learn about your mental health

Find out about medication & adult mental health services

Find out about employment & education

Learn more about your emotions & managing anger

Give graffiti art a try

Think about the future & staying well

Coping strategies – mindfulness, exercise, relaxation etc.

Peer support and Facebook Groups