



All-Wales  
Standard for  
People with  
Diabetes Moving  
from Paediatric to  
Adult Services  
within NHS Wales



# Foreword

We are delighted to introduce this All-Wales Standard for People with Diabetes Moving from Paediatric to Adult Services within NHS Wales. This standard is the product of research into good practice in Wales – learning from specialist clinicians, across all disciplines, in both paediatric and adult services.

Importantly, this standard also includes input and advice from people who have moved from paediatric to adult services, their parents, and adults diagnosed in their late teens, which is around the time young people normally start to receive care from adult services. Including the insights of people with diabetes in the creation of this Standard has helped identify how to tailor services to best serve young people as they mature into young adults.

When health boards introduce the recommendations in this standard they will be fulfilling the requirements of the Welsh Government's Diabetes Delivery Plan and delivering an exemplary service to young people living with diabetes. The recommendations are mapped across to the Healthcare Standards Wales, which all health boards have committed to implement.

Many recommendations in this Standard have been introduced, or are ready to be introduced, in health boards across NHS Wales through previous investment or the redistribution of existing resources. While there are some recommendations which may require investment, many of these recommendations can be introduced through changes in service planning at no net cost to health boards.

This is a great opportunity for Wales to lead the way in the UK to ensure that young people make the move to adult services safely and effectively as part of their journey towards long, healthy, productive lives with a reduced risk of severe complications.



Dr Julia Platts



Dr Chris Bidder



# Executive Summary

Around 96% of children and young people with diabetes in Wales have Type 1 diabetes. They are treated in specialist paediatric diabetes units, of which there are 14 in Wales. When young people with diabetes become adults there is an expectation that their care will transfer from paediatric services to adult services in secondary care. Becoming an adult is a very difficult period in life and a less than ideal time for change in care provision.

There is a large amount of evidence that a poor “transition” from paediatric to adult services has long-term effects in terms of disengagement with healthcare services and heightened risk of life-limiting complications and poor mental health. The first National Diabetes Transition Audit key findings indicate that young adults have fewer annual HbA1c measurements after transition, with higher average HbA1c scores. Other health indicators, eg cholesterol and blood pressure, also deteriorate post-transition. Young adults who experience a planned transition between the ages of 16 and 19 are most likely to benefit from regular engagement with healthcare services (NHS Digital 2017).

The benefits of a positive experience of moving from paediatric to adult services are documented in terms of improved clinical outcomes and quality of life. The long term benefit of improving the process by which young people come under the care of adult services could have a profound impact in the long-term outcomes of people with diabetes, with significant cost-saving implications for the NHS. This Standard outlines the components of successful transition clinics, with examples drawn from within Wales, which it is hoped could inspire similar processes in all health boards in Wales. When young people have completed the process they should be offered care in young adult clinics which should take place in appropriate environments. This is a recommendation for all health boards to implement (Welsh Government 2016).

This standard also introduces the main issues that teams will need to be aware of for this age group and this vulnerable period, including the delivery of structured education, advising on pregnancy and pre-conception, offering support as young people move away from home, caring for young people who are in prison or otherwise detained, and so on.

To support health boards fulfil their commitments, this document has also been mapped against the Welsh Government Health Care Standards throughout. In addition to the mapping out of Health Care standards, recommendations that all health boards should implement and develop within their young adult services are included at the end of each section with a summary of all recommendations included at the end of this document.

In conclusion, when NHS Wales health boards enact the recommendations in this Standard, the improvements in service will be reflected in improved outcomes in both the short and long-term.



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# Introduction

'Transition' is a common term for the process of a young person leaving the care of paediatric services and engaging with adult services. Although this term is commonly used throughout the clinical setting, all healthcare staff are advised that the word 'transition' has other common usage in society and therefore might not be the most suitable description to use with young people. It is suggested that clinics for young people between the ages of 16 and 25 are described as 'young adult clinics' instead of being called 'transition clinics'.

For the purposes of this Standard for Wales, the term transition will be used to describe the process of moving from one age-appropriate clinical setting to another over a period of time. Ensuring this is a safe and continuous process is a recognised priority in the Diabetes Delivery Plan for Wales, published in 2016, with the aim of providing high quality services to every young person moving on from the paediatric setting, wherever they live in Wales. In addition, the Welsh Government's emphasis on 'prudent healthcare' is reflected throughout this document, especially with regards to the reduction of immediate and long-term harm caused to young adults with diabetes, reducing unwarranted variation in services between hospitals and health boards, ensuring the efficient use of resources, and working co-productively with young adults with diabetes.

Paediatric and adult teams should work together to achieve continuity and the best services for young adults, including setting up young adult services where they do not already exist. This will mean paediatric and adults clinicians working jointly in their involvement with young people who are between 16-18, with adult colleagues taking over full responsibility of those under the age of 25 within a young adult service.

Diabetes from point of diagnosis onwards can have a significant impact on the life of a young person and their family or carers (NICE 2016). Promoting lifelong self-management of the condition is essential in achieving the most positive outcomes for the individual. This will need collaborative support through education and psychological services with crucial engagement needed between paediatric and young adult services during this time to ensure continuity of care and give young adults confidence in managing their diabetes through the transition process and beyond. Falling short of this can lead to serious and lasting consequences, for example through increased risk of mortality (Gordon 2012).

As stated in the Diabetes Delivery Plan for Wales (2016-2020), as part of ongoing care, children and young people with diabetes should receive support from a multidisciplinary paediatric diabetes team as defined by NICE. This includes specialist consultants, paediatric diabetes specialist nurses, diabetes specialist dietitians and paediatric psychologists. To ensure relational continuity, health boards are also to provide the appropriate services in adult care for those up to 25, which should also include psychological support as an integrated service provided on an 'opt out' basis. This means that all young people up to the age of 25 should be able to access specialist psychology support but will have the choice not to do so if preferred.

There is a growing awareness that many terms used by healthcare professionals can be unhelpful, whilst using positive language can increase positive engagement with healthcare professionals and an individual's health (Diabetes Australia, 2011). An example would be replacing the term 'diabetes control' with 'diabetes management' which indicates instead, a need to acknowledge that blood glucose levels can be influenced by the person with diabetes but not expect that they can ever be truly 'controlled' with all factors that influence blood glucose. A list of recommended replacement terms and rationale for healthcare professionals is included in appendix 1.

**Dignified  
Care**

**Timely  
Care**

**Individual  
Care**

**Staying  
Healthy  
Effective  
Care**

**Individual  
Care  
Staff and  
Resources**

**Dignified  
Care**

## Recommendation 1

Health boards should ensure individuals moving on from paediatric services should attend dedicated 'young adult clinics' suitable for those between the ages of 16 and 25 (and these should not be called 'Transition Clinics'). Both paediatric and adult healthcare professionals should work jointly with young people aged between 16-19 with the same adult healthcare staff continuing the young adult clinics with young adults up to the age of 25. Health boards should ensure that all paediatric diabetes teams include a multidisciplinary team (MDT) as defined by NICE, with an equivalent team in adult services to ensure continuity of this care up until the age of 25. Health boards should ensure that those under the age of 25 should be able to access specialist psychological support to help them manage their diabetes in the early stages of their adult lives.



### Moving to adult services – the wider context and the cost of failing to support people living with diabetes as they move from paediatric services

There is evidence that many young people do not have a good experience when they move to adult services and this has a negative impact on management of their diabetes (NHS England, 2016). This all-Wales Standard has been developed to support adult and paediatric teams to work together to smooth the transition process for young people between paediatric and adults diabetes services and to ensure young people in Wales receive the very best support at this time.

The National Transition Diabetes Audit shows that hospital admissions for diabetic ketoacidosis (DKA) peak between the ages of 16 and 20, particularly post-transition. Young adults aged 18 are seven times more likely to be hospitalised for DKA than children aged 12, and the vast majority of these will have moved to adult services (NHS Digital, 2017). This shows the immediate impact on in-patient beds with implications for service planning and a substantial cost impact to the NHS. This peak occurs during and immediately after the 'transition' period, and could be prevented with improvements in the process of moving to adult services. People diagnosed with Type 1 diabetes are most at risk of developing diabetic retinopathy, one of the leading causes of blindness in the UK (Thomas et al, 2017), underlining the importance of engaging with young people over this age grouping and encouraging eye screening. A large scale study in the USA shows that HbA1c scores spike upwards between the ages of 17 and 22 (Miller et al, 2015) and there is no counter-evidence to suggest that the situation is different in the UK – again this shows the importance of engaging with people with diabetes in this age group.

#### Individual Care

#### Person Centred Care

Diabetes clinicians should take into account the different needs of individuals in their care and provide a person-centred approach to ensure the best outcome for the young person. The care model described in this Standard indicate school years and suggested ages, but healthcare professionals can exercise discretion and clinical judgement when to begin the process with young people and their families, depending on circumstances.

#### Individual Care

Young adult services should also take into account the broader changes to a young person's life at this time. As well as dealing with diabetes, they may also be experiencing other concurrent life changes such as making career choices, attending further education or university, living independently, looking for their first job, taking a gap year or travelling, experimenting with alcohol and drugs, exploring their sexuality, dealing with bereavement, starting a family, as well as the interchange between primary and secondary care. These are examples and this list is by no means exhaustive. All of these changes can disrupt or impact daily routines which will impact on diabetes management.

#### Staying Healthy

Use of alcohol and tobacco seem to be equivalent in young people and young adults with diabetes and those without the condition. Alcohol, tobacco and other high risk behaviours such as substance misuse puts these individuals at risk for immediate and long term complications



related with diabetes (Peters & Laffel 2011). Young people with diabetes should have specific information that these behaviours can have on the management of their diabetes, rather than the general information that they are likely to receive elsewhere along with their peers who do not have diabetes under the personal and social education framework (Welsh Assembly Government, 2008).

The Diabetes Delivery Plan for Wales (2016-2020) notes the following:

*Transition from paediatric to adult services requires a flexible approach which meets the needs of the individual patient. The benefits of a successful transition are seen in increased clinic attendance and better health outcomes in the long-term. Young adults should be invited to co-produce transition services to ensure they work effectively for both service users and staff.*

*Services for young people with diabetes including young adults aged up to 25 will require engagement with both paediatric and adult diabetes services. The annual incidence of a diagnosis of diabetes is the same for those aged 16-20 and 20-25 and inevitably there will be higher numbers aged 19-25 in any locality. Both in-patient and out-patient diabetes care for those aged 19-25 will most usually take place in adult services, most certainly when diabetes first presents at this age. The majority of these cases will be Type 1 diabetes which is different to the majority of diabetes seen in adult services.*

There are significant mortality and morbidity risks in relation to young people's acute and long-term health and wellbeing if they are unable to safely manage their diabetes. Disengagement with health services makes unsafe management more likely (Gordon, 2012). Between the ages of 20 and 39, men with diabetes face a mortality risk of 2.54 times higher than men without diabetes. Women with diabetes face a mortality risk of 3.76 times higher than women who do not have diabetes. Much of this risk is carried by men and women with Type 1 diabetes. Many of these risks result from disengagement with diabetes services as they left paediatric services.

10 per cent of the annual NHS Wales budget is spent on diabetes care, which equates to about £500m a year. Eighty per cent of this figure is spent on managing complications, most of which could be prevented (Diabetes UK). The point of transfer between paediatric and adult services and engagement with a new team and culture in adult health care is a potential risk escalator, but can also be viewed as an opportunity to support effective management and engagement.

In addition to adverse impact on health, social and educational outcomes for the young person and their carers, a poor experience of the transition process impacts on resources in health care and other agencies through repeated non-attendance for planned care, increased use of urgent/out of hours care and increased complexity of need through secondary and avoidable complications, such as eye health and vascular problems. (NHS England 2016)

The impact of preventable diabetes complications can add a significant burden to already overwhelmed healthcare systems, increase unemployment, reduce job productivity and increase cost of disability. The presence of diabetes complications increases NHS costs more than five-fold, and increases by five the chances of a person needing hospital admission (NHS England, 2016).

Effective  
Care

Timely  
Care

## Recommendation 2

**Healthcare professionals should ensure that appropriate and specific information is provided about the risks that alcohol, smoking and substance misuse can have on their Type 1 diabetes management. Health boards should invite young people to co-produce their young adult services to ensure they work effectively for both people who use the service and staff. Health boards should ensure that both healthcare professionals from paediatric and adult services who engage with young people and young adults work together so that the information provided reflects the same key messages.**

# Mental health and diabetes

## Staying Healthy

Mental health problems have significant co-morbidity in young people with Type 1 diabetes. Prevention of mental health issues and promotion of psychological resilience should be a priority. Good emotional and mental wellbeing and support can promote vital resilience at this time and can encourage more positive diabetes management (NHS England).

Psychosocial challenges are common during emerging adulthood, occur more often in those with diabetes compared with those without diabetes, and occur more commonly during emerging adulthood than during other stages of life. Living with diabetes often brings with it a broad range of diabetes-related distresses (Peters & Laffel, 2011). A number of screening tools are included in the appendix.

Psychological issues (such as anxiety, depression, behavioural problems, eating disorders, conduct disorders and family conflict) have a significant and adverse impact on the management of type 1 and type 2 diabetes, and the general wellbeing of children and young people and their family members or carers (Nice 2016).

## Timely Care

NICE and the paediatric peer review process prioritise specialist psychology services being offered as a matter of course to children and young people (NICE 2015). This should be a standard part of support services and clinical appointments, with dedicated clinical psychology posts embedded in the paediatric and adult diabetes teams to engage with young adults as part of their young adult clinics. This is supported in the Diabetes Delivery Plan 2016-2020. This emphasis on psychological support needs to continue in adult services during and after the process of transition. Currently, psychological support is variable in NHS Wales and provision should be addressed by health boards.

## Staff and Resources

Observed good practice in Wales at Wrexham Maelor Hospital, Betsi Cadwaladr University Health Board shows the value of a psychologist working as part of the transition process and alongside the young adult team, performing the following functions:

- 1) Being present as part of the MDT during clinic appointments
- 2) Co-ordinating and evaluating clinic screening programme
- 3) Providing specialist assessment, formulation, signposting and psychological intervention for individuals identified with distress
- 4) Providing supervision, consultation and training for the multidisciplinary diabetes team
- 5) Conducting audit and research to advance knowledge and service development in Wales

## Recommendation 3

**Health boards should ensure specialist clinical psychology services are offered as a standard part of support services and clinical appointments, with dedicated clinical psychology posts embedded in the paediatric and adult diabetes teams and involved in the transition process.**

# Type 1 diabetes, disordered eating and eating disorders

People living with Type 1 diabetes are more vulnerable to developing eating disorders (Diabetes UK).

There is a strong association between insulin omission and disordered eating, which is complicated by important diabetes-specific factors. People living with diabetes who are preoccupied with eating and weight concerns may also become emotionally overwhelmed by diabetes and/or fearful of normoglycemia and the associated weight-related consequences, thus reinforcing the desire to omit insulin and maintain elevated blood glucose levels (Polonsky et al, 1994). Disturbed eating behaviours are common where manipulation of insulin or hypoglycaemic agents is used to manage body weight and/or deal with their condition, informally known as 'diabulimia'.

Research suggests women with Type 1 diabetes are twice as likely to develop anorexia or bulimia, and that 60 per cent of Type 1 women will experience a 'clinically significant' eating disorder by the time they are 25 (Colton et al, 2015). Research shows men living with Type 1 diabetes have a "higher drive for thinness" than their counterparts who do not have diabetes, making them also more susceptible to an eating disorder (Svensson et al, 2003).

When delivering diabetes services to young people as they move between services or in young adult clinics, health boards should be aware of this increased risk of eating disorders, insulin omission and disordered eating. It is recommended that screening tools are used, alongside additional staff training and supervision by a psychology professional to ensure those at risk can be properly supported. A screening tool currently being used in Wales is included in appendix 2. These measures should only be employed in conjunction with a thorough clinical assessment by suitable medical and psychology professionals. Referral pathways between diabetes services and eating disorder services should be developed and followed. People with diabetes who also have significant eating disorder behaviours and diabetes should be classified as 'high risk' and have immediate access to specialist eating disorder services who must work in conjunction with the multidisciplinary diabetes team to formulate a person-centred assessment and intervention plan.

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## Recommendation 4

**Health boards should be aware of the increased risk of eating disorders, insulin omission and disordered eating and validated screening tools should be used alongside additional staff training and supervision by a psychology professional. Health boards should develop and implement referral pathways between diabetes and eating disorder services to ensure the right support is available and accessible for the individual. People with diabetes who also have significant eating disorder behaviours and diabetes should be classified as 'high risk' and have immediate access to specialist eating disorder services.**



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## Children and young people with young onset Type 2 diabetes

### Individual Care

In the UK, the care of young people with diabetes has focused predominantly on Type 1 diabetes. However, young-onset Type 2 diabetes has become increasingly prevalent and health boards should ensure that services for young people with young onset Type 2 diabetes also have their specific needs met including receiving Type 2 specific education. There is evidence that young people with Type 2 diabetes are at more risk of developing both microvascular and macrovascular complications than young people with Type 1 diabetes, in particular, ischemic heart disease and neuropathy (SH Song, 2015). Therefore, this cohort of young people should also follow the transitional process into the young adult clinic within secondary care until the age of 25. Under no circumstance should they be discharged to Primary Care.

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### Recommendation 5

**Healthcare professionals should ensure that young people with young onset Type 2 diabetes follow the transitional process into the young adult clinic within secondary care until the age of 25. People with young onset Type 2 diabetes should receive Type 2 specific education.**

## Structure of service development

The development of any service should be considered according to three stages of transition; paediatric preparation, planned transfer of care, and supported integration into adult services and new care settings (eg primary care).

Welsh Government has circulated draft guidance on healthcare services for 16 and 17 year olds, (Welsh Government, 2017) which recognises 5 principles, where health boards should regard the following:

- Ensure the needs of the young people are paramount, with safe processes which are fit for purpose
- Be child and family centred, putting the young person at the heart of service delivery by promoting access to care and support, particularly for children in crisis and for those with protected characteristics
- Involve the young person and their representatives and be responsive to their wishes, feelings and needs in planning and delivering transition
- Work in partnership with other healthcare services and other agencies and disciplines across social and education services and voluntary agencies to meet the needs of the young person with robust processes wherever transfers of care are required
- Have strong governance structures with assurance through planning, review and reporting arrangements, ensure feedback that captures the voice of the young person

Further to this, the Children and Young People's Diabetes Network (& Brecon Group) convened a Transition Working Group in 2016, which assessed the clinical evidence for best practice. The group summarised the relevant research findings (Allen et al, 2010) regarding the importance of continuity of care for children and young people as they move into young adult and adult services. The continuities they identified are as follows:

- 'experienced continuity' – the experience of a coordinated and smooth progression of care
- 'relational continuity' – an ongoing therapeutic relationship between the patient and one or more healthcare professionals
- 'longitudinal continuity' – uninterrupted relationships with the service providers over time
- 'management continuity' – ensuring diabetes management is consistent with needs through a common purpose or plan
- 'cultural continuity' – a seamless progression from child to adult service culture across service interfaces
- 'flexible continuity' – flexible adjustment to the needs of an individual over time
- 'developmental continuity' – care which grows with the changing demands of the client group and works to facilitate that change
- 'informational continuity' – the provision of information so young people and their families are prepared for transition and understand the new arrangements for their care

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### Recommendation 6

**Health boards should ensure that the development of any service should be considered according to the three stages of transition; paediatric preparation, planned transfer of care and supported integration into adult services and new care services. Healthcare professionals should involve the young person and their representatives and be responsive to their wishes feelings and needs in planning and delivering transitional care to adult services. Health boards should ensure that feedback from individuals is captured where the voice of the young person is heard and at the centre of care. The transition process and young adult service should ensure continuity of care, across all aspects of the service.**

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## Advice for parents and carers

Whilst transition is often focused around the needs of the young person, it should be noted that the parents and carers are also often undergoing their own changing circumstances in the ways they support and care for the young person.

Parents have separate needs that should be accounted for in the transition process and young adult service especially in the way that they are communicated with, the information that they need and how it is provided as well as in support of the parallel change those parents often make (NHS England, 2016). Advice and support should be offered to parents and carers about other services and support that they may be entitled to receive.

At the start of the process of moving to adult services, information should be provided specifically to the parent to address issues they are likely to face in formats or using methods that are familiar and accessible including the option of provision of separate consultation sessions.

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### Recommendation 7

**Healthcare professionals should ensure that the separate needs of the parent or carer is also accounted for in the initial transitional care process as the young person begins their journey through the young adult service. Healthcare professionals should provide advice and support specifically to parents and carers about available services and support.**



## Early preparation for the move to adult services

Good outcomes have been achieved where clinics have implemented models in which there is a gradual and well planned move from paediatric consultations to joint paediatric and adult consultations through to adult consultations. In this model the young person has the opportunity to have independent sessions with clinicians and there is a specific service to meet the needs of parents.

Discussions about moving to adult services should start when children enter school year 9 (age 13). This means the discussion can start with the discussions around which GCSE subjects they are choosing with a wider discussion about what they want to do in later life. One of the key messages at this point is that diabetes should not be seen as a barrier to achievement. It is also important for teenagers to understand their management of diabetes will need to continually adjust in light of changes in their life, eg taking into account changes in routine, revision schedules, exams, part-time work and learning to drive and the subtle impact that daily stresses can have on diabetes management.

Early preparation and planning for the transition period is essential in managing expectations, promoting understanding and involvement of the wider process, and ensuring the young person is well informed and therefore empowered. Planning must be based on the young person's physical development, emotional maturity and local circumstances.

As young people near the point of transfer to adult services, they should receive structured education. This should be the relevant SEREN module, which will continue the education programme that is used in all paediatric units. This module is due for delivery in early 2018. In addition, once the young person is being cared for in adult services, they should also receive appropriate dietetic education, for example, attending a DAFNE carbohydrate counting course or other course that will be useful for people to self-manage their diabetes. Delivery of DAFNE or other courses in a young adult's cohort is preferable. Young adults should be prioritised for education courses as this represents the greatest return on investment for health boards in terms of prevention and the length of time influenced by education.

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### Recommendation 8

**Health boards should ensure that there are transitional care processes implemented through clinics that follow a model in which there is a gradual and well planned move from paediatric consultations to joint paediatric and adult consultations before full consultation with adult clinicians in a young adult service. Healthcare professionals should ensure discussions about moving to adult services should start when children enter school year 9 along with discussions of career and life choices. Healthcare professionals should ensure young people nearing the point of transfer to adult services should receive structured education. This should be the relevant SEREN module. Healthcare professionals should ensure young adults receive appropriate dietetic education, for example, attending a DAFNE course, preferably in an education group composed of people of a similar age. Young adults with Type 2 diabetes should receive Type 2 specific education.**

## Planned handover

It is essential that the young person is well prepared prior to their handover, and throughout the process. Paediatric and adult healthcare teams need to work jointly to provide assessment and service to young people with diabetes. The lead clinicians need to be clearly identified, especially when the paediatric service hands the patient over to the adult team. All young people should have named healthcare professionals and be clear in how they are able to contact them appropriately for advice in between clinic appointments.

Through identifying best practice in Wales, the model of care in Wrexham Maelor Hospital has been noted as meeting the five principles identified by Welsh Government, and also ensuring continuity of care as identified by the Children and Young People's Wales Diabetes Network Transition Working Group. A summary of the Wrexham model is available in appendix 3. Similar models have also been introduced in Prince Charles Hospital in Merthyr Tydfil (see appendix 4) and Cardiff and Vale UHB.

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### Recommendation 9

**Health boards should ensure that paediatric and adult healthcare teams are able to work jointly to provide assessment and service to young people with diabetes. Health boards should ensure that all young people should have named healthcare professionals allocated to them. Healthcare professionals should ensure that each young person is aware of who their named worker is and be clear in how they are able to contact them appropriately for advice between clinic appointments. Health boards should ensure their model includes continuities in process and should consider structuring their clinics along similar lines to the models adopted at Wrexham Maelor Hospital and Prince Charles Hospital, Merthyr Tydfil (See appendix 3 and 4).**



## Young adult clinics

Healthcare teams should work jointly to provide young adult services that are wrapped around and are responsive to the needs and preferences of the young person. Diabetes care for those aged 19-25 may be best provided in dedicated clinics with the same staff from adult services they have met during the process of moving to adult services. Young adult clinics have been included in the Welsh Government's Diabetes Delivery Plan as recommended best practice for all health boards to implement.

When health boards have established young adult clinics, any young people diagnosed between the ages of 17-25 should attend these clinics rather than other adult clinics. Newly diagnosed young adults should receive diabetes structured education, preferably within the first six weeks of diagnosis, depending on their circumstances. Consideration should be given to the clinical environment where young adult clinics take place, to ensure, for example, that messaging in waiting areas is of use to young adults with diabetes. Good practice seen in Wales includes the use of a 'Meet the Team' board with photos of all members of the diabetes team, including medical and support staff like secretaries. It is also useful to list the services that are available. A visual example of good practice of this, from the Adult Diabetes Team at the Diabetes Centre, Prince Charles Hospital, Cwm Taf University Health Board is included in appendix 5.

There is growing evidence that healthcare professionals working alongside trained youth workers and those with experience of engaging young people in youth settings achieve better outcomes with young people including HbA1c reduction (Peacock et al. 2016). Youth workers or youth engagement officers can be used to aid young people's disengagement with services, help sign post to relevant support in a wider context than solely their condition and promote empowerment and independence. Health boards should explore appointing a youth worker to provide additional support to young people and young adults with diabetes. This youth worker should be embedded within the health boards' young adult clinic team and work with both paediatrics and young adult services to help young people moving between services.

Immunisation, for example flu vaccination, should be promoted at young adult clinics and offered through young adult clinics where this is possible.

### Staff and Resources

### Staff and Resources

## Recommendation 10

**Healthcare teams should work jointly to provide young adult clinics within adult services that are wrapped around and are responsive to the needs and preferences of the young person until they are 25. Healthcare professionals should ensure all newly diagnosed young adults receive diabetes structured education within the first six weeks of diagnosis and attend young adult clinics. Health boards should appoint a youth worker to sit within the young adults' service to work with those aged 11-25 to provide additional and further support to young people and young adults with diabetes and prevent disengagement with services. Health boards should ensure that immunisation is promoted at young adult clinics and relevant vaccinations are offered through young adult clinics wherever possible.**



## Need for flexible working

### Individual Care

The Diabetes Delivery Plan states transition services require a flexible approach which meets the needs of the individual living with diabetes. The benefits of a successful move to adult services are seen in increased clinic attendance and better health outcomes in the long-term (Welsh Government 2016-2020). This flexible approach should be part of the broader young adult service that is offered up until the age of 25 years also included in the Diabetes Delivery Plan.

### Dignified Care

Health boards should recognise the need for young adult friendly communication in all aspects of this, with best practice recognising young adult friendly clinic letters, clinic times, and clinic reminders via text/email where possible and the use of technology to help aid communication and capture windows of opportunity. Young adults may also wish to bring a partner or family member with them to clinic and this should be accommodated by healthcare professionals, where it is the wish of the young person.

Young adults may also be reliant on others in bringing them to clinic and therefore it should be taken into consideration that they may not always be able to attend appointments. Local teams should recognise those who do not attend several consecutive appointments with more than one form of communication in an attempt to re-engage them with diabetes services. Measures should be taken by health boards to ensure that young adults who may disengage from services for a period of time are not lost in the system between referrals between secondary and primary care with no follow-up. Young adults with diabetes under the age of 25 should under no circumstances be discharged to primary care without a full discussion with the person with diabetes.

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### Recommendation 11

**Healthcare professionals should use appropriate language and a variety of methods of communication when communicating with young people and young adults including the use of technology where possible. Healthcare professionals should ensure young people and young adults are made aware that they are able to bring someone with them, such as a partner or other trusted adult, into their consultation. Healthcare professionals should attempt to re-engage those who do not attend more than one consecutive appointment with an alternative method of communication. Health boards should ensure those under the age of 25 should not be discharged under any circumstance to primary care without a full discussion with the individual.**

## Peer support

There is evidence to suggest that professionally led support groups may help improve diabetes outcomes in young adults with Type 1 diabetes, including improvement in HbA1c, improved mental health and more consistent self-care (Markowitz & Laffel, 2012).

The Diabetes Delivery Plan for Wales proposes a mechanism of peer support and mentorship working with young people, volunteers and third sector organisations should be created. This could include opportunities to meet with other young people with diabetes in local areas. Young adult clinics should have information of local peer support groups available and assist individuals who express an interest in setting up such groups.

Health boards should exercise the use of group education that will allow an opportunity of peer support to be facilitated by clinical teams as part of ongoing diabetes education for the individual. Health care professionals should be confident in facilitating these sessions with young adults and topics relevant to young adult needs. A group education session can be a good starting point for an ongoing peer support group, as young people get to know each other through the education programme and can then continue meeting. Staff are encouraged to use the SEREN structured education module that is in development as a catalyst to creating a peer support group.

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### Recommendation 12

**Health boards should provide group education and use that as a catalyst towards creating a peer support group.**

## Continuity of care when young people change locality

All units should provide information for the Wales Diabetes Services Directory so that young adults can be put in touch with age-appropriate adult services if they move within Wales. This information will be shared with English Networks, for young adults who may also move outside of Wales. Health boards will be contacted and ask to supply relevant information for this directory.

Healthcare professionals working with young adults should work closely with universities to assist in care plans for students in further education and to care for students who have moved into the area if those students want to transfer their care to centres near their place of study. Young adults who do not wish to transfer their care to another area should be offered clinic appointments in co-ordination with the university academic year when the individual will be returning home for academic holidays wherever possible. Health boards should also consider providing technological support in order to facilitate remote appointments through a virtual clinic over the telephone or using a service such as Skype for virtual consultations.

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### Recommendation 13

**Healthcare teams should provide accurate information for the Wales Diabetes Services Directory, when information is requested. Healthcare professionals should work closely with universities to assist with care planning. Healthcare professionals should discuss with young adults whether they want to transfer their care or stay with their current team when moving to university. Healthcare professionals should allow young adults who do not wish to transfer their care to be given clinic appointments in co-ordination with the university academic year. Virtual appointments can also be used.**

.....

**Individual  
Care**



.....

**Individual  
Care**

## Staying Healthy

# Preconception care and pregnancy

Young women with Type 1 diabetes should receive appropriate information on the importance of preconception planning and pregnancy as defined by (NICE 2016). Pregnancy should be discussed with them to ensure the information is understood by the young person. Clinicians should be mindful that it may not be desirable or appropriate for the young person to discuss this with parents present and the opportunity for this to be discussed on their own should be offered.

## Effective Care

If a young woman with diabetes presents to clinical teams when pregnant, she should be referred to diabetes antenatal clinic as soon as possible. Contact should be retained with her diabetes specialist nurse to allow continuity and support. Post-delivery, the young person should attend young adult clinics. In the event of the young person still being under the care of the paediatric diabetes specialist nurse, opportunity should be given for the young person to meet the diabetes specialist nurse that works within the young adult clinic so that she will be familiar with staff after delivery of her baby.

### Recommendation 14

**Health care professionals should ensure young women receive appropriate information on the importance of preconception planning and pregnancy as defined by (NICE 2016). Healthcare professionals should refer any young woman who presents with diabetes when pregnant to diabetes antenatal clinic as soon as possible. Healthcare professionals should ensure that all young women under the age of 25 attend young adult clinics after giving birth.**

# Young offenders and young adults within a prison setting

When circumstances occur where a person with diabetes may end up in a young offender's institute or prison, they will also need to access the right support for them to best manage their diabetes through this time and may need additional support on their release. Clinicians should follow NICE guidelines NG43 if the offender is under 18 and NG57 if the offender is over 18, which are referenced.

### Recommendation 15

**Healthcare professionals should follow NICE guidelines NG43 and NG57 if offenders are over 18 to ensure that young people and young adults are able to manage their diabetes whilst in young offender's institutes or prison settings. Healthcare professionals should ensure that all young offenders under the age of 25 attend young adult clinics after their release.**

## Quality assurance

The Diabetes Delivery Plan 2016-2020 highlights the importance of quality assurance through involvement of the National Diabetes Audit (for adult services) or the National Paediatric Diabetes Audit (for children's services) and participation in a peer review system. The findings of these audits and reviews should be publicly available to provide assurance to people with diabetes that they are receiving high quality care. The published figures can also identify good practice and outcomes to inform quality improvement efforts to raise standards. All units should take part in Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs) and this feedback should also be made publicly available. PROMs should include an age appropriate measure of depression (eg PHQ-9), anxiety (eg GAD-7) and diabetes distress (eg DDS). All of these measures are available in the appendix.

Following the evidence outlined above, and the models that are available for the adoption in Wales, the following measures should be used to assess the quality of services offered to young adults between the ages of 16 and 25.

### Outcome Measures

- Mean adjusted HbA1C measures (all patients in unit) including percentage of patients with HbA1c below 58mmol/mol and percentage of patients with HbA1c above 75mmol/mol
- Number of patients receiving all required care processes as defined by NICE
- Clinic DNA (did not attend) rates
- Percentage of patients not attending clinic for 6/9/12+ months
- Number of patients being referred for diabetes complications (eg retinopathy)

### Process Measures

- All people with diabetes age 19-25 being seen in a young adult clinic
- Transition takes place over a number of joint clinics with paediatric and adult services
- Patients have a named contact health care professional
- Percentage of patients completed structured education (either while preparing for transition or within six weeks of diagnosis if diagnosed aged 18 or over)
- PREMs and PROMs scores

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## Recommendation 16

**Health boards should ensure all units take part in Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs) and this information should be made publicly available. PROMs should include age appropriate measures of depression, anxiety and diabetes distress. A list of measures is included in the Appendix.**



# Summary of Recommendations



## Recommendation 1

Health boards should ensure individuals moving on from paediatric services should attend dedicated 'young adult clinics' suitable for those between the ages of 16 and 25 (and these should not be called 'Transition Clinics'). Both paediatric and adult healthcare professionals should work jointly with young people between 16-19 with the same adult healthcare staff continuing the young adult clinics with young adults up to the age of 25. Health boards should ensure that all paediatric diabetes teams include a multidisciplinary team as defined by NICE, with an equivalent team in adult services to ensure continuity of this care up until the age of 25. Health boards should ensure that those under the age of 25 should be able to access specialist psychological support to help them manage their diabetes in the early stages of their adult lives.

## Recommendation 2

Healthcare professionals should ensure that appropriate and specific information is provided about the risks that alcohol, smoking and substance misuse can have on their Type 1 diabetes management. Health boards should invite young people to co-produce their young adult services to ensure they work effectively for both people who use the service and staff. Health boards should ensure that both healthcare professionals from paediatric and adult services who engage with young people and young adults work together so that the information provided reflects the same key messages.

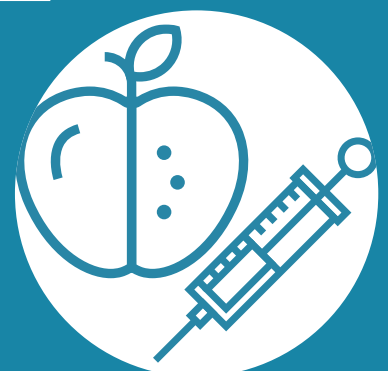


## Recommendation 3

Health boards should ensure specialist clinical psychology services are offered as a standard part of support services and clinical appointments, with dedicated clinical psychology posts embedded in the paediatric and adult diabetes teams and involved in the transition process.

## Recommendation 4

Health boards should be aware of the increased risk of eating disorders, insulin omission and disordered eating and validated screening tools should be used alongside additional staff training and supervision by a psychology professional. Health boards should develop and implement referral pathways between diabetes and eating disorder services to ensure the right support is available and accessible for the individual. People with diabetes who also have significant eating disorder behaviours and diabetes should be classified as 'high risk' and have immediate access to specialist eating disorder services.



### Recommendation 5

Healthcare professionals should ensure that young people with young onset Type 2 diabetes follow the transitional process into the young adult clinic within secondary care until the age of 25. People with young onset Type 2 diabetes should receive Type 2 specific education.

### Recommendation 6



Health boards should ensure that the development of any service should be considered according to the three stages of transition; paediatric preparation, planned transfer of care and supported integration into adult services and new care services. Healthcare professionals should involve the young person and their representatives and be responsive to their wishes feelings and needs in planning and delivering transitional care to adult services. Health boards should ensure that feedback from individuals is captured where the voice of the young person is heard and at the centre of care. The transition process and Young adult service should ensure continuity of care, across all aspects of the service.

### Recommendation 7

Healthcare professionals should ensure that the separate needs of the parent or carer is also accounted for in the initial transitional care process as the young person begins their journey through the young adult service. Healthcare professionals should provide advice and support specifically to parents and carers about available services and support.



### Recommendation 8

Health boards should ensure that there are transitional care processes implemented through clinics that follow a model in which there is a gradual and well planned move from paediatric consultations to joint paediatric and adult consultations before full consultation with adult clinicians in a young adult service. Healthcare professionals should ensure discussions about moving to adult services should start when children enter school year 9 along with discussions of career and life choices. Healthcare professionals should ensure young people nearing the point of transfer to adult services should receive structured education. This should be the relevant SEREN module. Healthcare professionals should ensure young adults receive appropriate dietetic education, for example, attending a DAFNE course, preferably in an education group composed of people of a similar age. Young adults with Type 2 diabetes should receive Type 2 specific education.





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### Recommendation 9

Health boards should ensure that paediatric and adult healthcare teams are able to work jointly to provide assessment and service to young people with diabetes

Health boards should ensure that all young people should have named healthcare professionals allocated to them. Healthcare professionals should ensure that each young person is aware of who their named worker is and be clear in how they are able to contact them appropriately for advice between clinic appointments. Health boards should ensure their model includes continuities in process and should consider structuring their clinics along similar lines to the model adopted at Wrexham Maelor Hospital and Prince Charles Hospital, Merthyr Tydfil (See appendix 3 and 4).

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### Recommendation 10

Healthcare teams should work jointly to provide young adult clinics within adult services that are wrapped around and are responsive to the needs and preferences of the young person until they are 25. Healthcare professionals should ensure all newly diagnosed young adults receive diabetes structured education within the first six weeks of diagnosis and attend young adult clinics. Health boards should appoint a youth worker to sit within the young adults' service that work with those aged 11-25 to provide additional and further support to young people and young adults with diabetes and prevent disengagement with services. Health boards should ensure that immunisation is promoted at young adult clinics and relevant vaccinations are offered through young adult clinics wherever possible.



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### Recommendation 11

Healthcare professionals should use appropriate language and a variety of methods of communication when communicating with young people and young adults including the use of technology where possible. Healthcare professionals should ensure that young people and young adults are made aware that they are able to bring someone with them, such as a partner, into their consultation. Healthcare professionals should attempt to re-engage those who do not attend more than one consecutive appointment with an alternative method of communication. Health boards should ensure those under the age of 25 should not be discharged under any circumstance to primary care without a full discussion with the individual.





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### Recommendation 12

Health boards should provide group education and use that as a catalyst towards creating a peer support group.

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### Recommendation 13

Healthcare teams should provide accurate information for the Wales Diabetes Services Directory, when information is requested. Healthcare professionals should work closely with universities to assist with care planning. Healthcare professionals should discuss with young adults whether they want to transfer their care or stay with their current team when moving to university. Healthcare professionals should allow young adults who do not wish to transfer their care to be given clinic appointments in co-ordination with the university academic year. Virtual appointments can also be used.



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### Recommendation 14

Health care professionals should ensure young women receive appropriate information on the importance of preconception planning and pregnancy as defined by (NICE 2016). Healthcare professionals should refer any young woman who presents with diabetes when pregnant to Diabetes Antenatal clinic as soon as possible. Healthcare professionals should ensure that all young women under the age of 25 attend young adult clinics after giving birth.



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### Recommendation 15

Healthcare professionals should follow NICE guidelines NG43 and NG57 if an offender is aged over 18 to ensure that young people and young adults are able to manage their diabetes whilst in young offender's institutes or prison settings. Healthcare professionals should ensure that all young offenders under the age of 25 attend young adult clinics after their release.



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### Recommendation 16

Health boards should ensure all units take part in Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs) and this information should be made publicly available. PROMs should include age appropriate measures of depression, anxiety and diabetes distress. A list of measures is included in the appendix.





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# APPENDIX 1

## Examples of language to be avoided, rationale and examples of preferred language

Avoid	Rationale	Use
Diabetic, sufferer, patient	The term 'diabetic' defines the individual as their health condition. It is better to emphasise the person's ability to live with diabetes. Labelling someone as 'diabetic' positions diabetes as the defining factor of their life. The term 'sufferer' is too negative to be used to refer to all people with diabetes. If you refer to someone as 'suffering from diabetes', is that really true? Does it have to be true? While some people may find diabetes management and its complications challenging and distressing, not everyone 'suffers' with diabetes. Referring to people with diabetes as 'diabetic sufferers' positions them as helpless victims, powerless to lead a normal life with diabetes. The term 'patient' implies the person is a passive recipient of care, rather than an active agent in his or her own self care. Patients are people, and people are individuals, with their own preferences, priorities and lives beyond diabetes.	Person with diabetes, person living with diabetes
Disease	Disease has negative connotations of something that may be contagious and nasty. People with diseases are often avoided or feared. Diabetes is a chronic condition that the person will live with for the rest of their life.	Condition
Normal, healthy (person, blood glucose levels etc)	Referring to people who do not have diabetes as 'normal' implies that people with diabetes are 'abnormal'. This is not the case and not the point. Similarly, referring to 'normal blood glucose levels' implies that levels outside this range are 'abnormal'.	People without diabetes; target, optimal blood glucose
Obese, normal weight	The term 'obese' is frequently used to label a person, eg 'he or she is obese', in a way that frames excess weight as a trait rather than a state. A trait is something we have to live with (like personality), a state is something that can change. Furthermore, with excess weight fast becoming the norm in society, the term 'obese' does not convey the message that excess weight puts health at risk. Nor does it suggest to the person that he or she has the power and the means to change this risk factor.	Unhealthy, healthy weight
Describing the person (eg 'he or she is ... poorly controlled, cooperative, uncooperative')	Describing the person rather than the behaviour implies the behaviour will not and cannot change. It has a fatalistic connotation. People with diabetes need to think of HbA1c and blood glucose levels as changing indicators that respond to a variety of factors. When health professionals use such labels, it suggests that they may have given up. Furthermore, it is futile to try to 'make' people change their behaviour or self-care activities. Diabetes care requires a collaborative approach, not persuasion or coercion.	Words that describe outcomes or behaviours ('his or her blood glucose is high')

Avoid	Rationale	Use
Poor control, good control, well controlled (referring to HbA1c or blood glucose levels)	Referring to 'poor' or 'good' control infers a moral judgment about the outcome, i.e. the person with diabetes has been good or bad. No-one needs criticism when things are not going well. Taking the judgment out of the language acknowledges that a variety of factors affect optimal diabetes management, many of which are beyond the person's control. Furthermore, the individual's efforts need to be acknowledged regardless of the outcome.	Stable / optimal blood glucose levels, within the optimal range, or within the target range; suboptimal, high/low
Control (eg diabetes control, blood glucose control, controlling diabetes)	The idea of controlling blood glucose levels is great in theory, as few people would want to be 'out of control'. However, assuming that true 'control' can be achieved dismisses the fact that blood glucose levels are influenced by many factors outside of the person's direct control (eg hormones, illness, stress, prolonged / delayed effects of physical activity, other medications). Continually striving to 'achieve control' or 'maintain control' is ultimately a recipe for feelings of guilt, despair and frustration when it cannot be achieved. Instead, we need to acknowledge that blood glucose levels can be influenced by the person with diabetes but not expect that they can ever be truly 'controlled'.	Manage, influence
Should, should not, have to, can't, must, must not	The individual is an expert in his or her own diabetes. Giving instructions about what he or she should (or should not) do implies that: (a) you know better, and (b) not following the instruction renders the person morally deficient or uncooperative. Suggesting treatment options emphasises the individual's choices, acknowledges his or her autonomy and that he or she has ultimate responsibility for his or her own health.	You could consider..., you could try..., consider the following options..., you could choose to...
Failed, failing to...	'Failure' implies that one has aimed and missed the target. It implies lack of achievement, ineffective efforts or lack of effort. It also implies disappointment on the part of the person using the term. It is better in most circumstances to rely on facts and avoid judgments about the facts.	Did not, has not, does not...
Compliance, compliant; noncompliance, non-compliant; adherence, adherent, nonadherent	The terms 'compliance' and 'adherence' refer to the extent to which behaviour matches the prescriber's recommendations. They imply a lack of involvement in decision-making by the person with diabetes. They assume the health professional's guidance was clear, does not conflict with advice of others, and that the person with diabetes recalls the instruction clearly. They also imply that people who do not comply or adhere are irresponsible or uncooperative. There is no single, convenient alternative term. Diabetes management requires active, collaborative decision-making, taking into account the individual's preferences and priorities.	Words that describe collaborative goal-setting



Avoid	Rationale	Use
Chances (of complications etc)	Complications are not destiny nor are they entirely due to bad luck. Talking about the individual's 'chances' of developing complications suggests the person has no control over his or her future. It dismisses the very real efforts needed to delay or prevent their onset. Focusing on the individual's actual risk and what he or she can do to minimise it is more pro-active.	Health risks; risk of complications
Blood tests, testing	'Tests' imply success or failure and an end result. Rather, people with diabetes need to monitor their changing blood glucose levels throughout their lives	Checking, monitoring, self monitoring
'Treating this patient'	Referring to 'treating this patient' implies something done to the person rather than the diabetes and ignores the active role of the person with diabetes. 'Managing diabetes' enables the person with diabetes to actively engage in decision-making and management of their own condition.	Managing diabetes

(Adapted from Diabetes Australia 2011.)



# Diabetes Eating Problem Survey (DEPS-R)

Name: .....

Hospital No:.....

Date of completion: .....

## APPENDIX 2

This form has 16 statements about food and diabetes.

Please rate how often each statement applies to you using the following scale:

Never	Rarely	Sometimes	Often	Usually	Always
0	1	2	3	4	5

1. Losing weight is an important goal to me	0	1	2	3	4	5
2. I skip meals and/or snacks	0	1	2	3	4	5
3. Other people have told me that my eating is out of control	0	1	2	3	4	5
4. When I overeat, I don't take enough insulin to cover the food	0	1	2	3	4	5
5. I eat more when I am alone than when I am with others	0	1	2	3	4	5
6. I feel that it's difficult to lose weight and control my diabetes at the same time	0	1	2	3	4	5
7. I avoid checking my blood sugar when I feel like it is out of range	0	1	2	3	4	5
8. I make myself vomit	0	1	2	3	4	5
9. I try to keep my blood sugar high so that I will lose weight	0	1	2	3	4	5
10. I try to eat to the point of spilling ketones in my urine	0	1	2	3	4	5
11. I feel fat when I take all of my insulin	0	1	2	3	4	5
12. Other people tell me to take better care of my diabetes	0	1	2	3	4	5
13. After I overeat, I skip my next insulin dose	0	1	2	3	4	5
14. I feel that my eating is out of control	0	1	2	3	4	5
15. I alternate between eating very little and eating huge amounts	0	1	2	3	4	5
16. I would rather be thin than to have good control of my diabetes	0	1	2	3	4	5

Total Score:

Markowitz, J. T., Butler, D. A., Volkening, L. K., Antisdel, J. E., Anderson, B. J., & Laffel, L. M. (2010). Brief screening tool for disordered eating in diabetes. *Diabetes care*, 33(3), 495-500.



# APPENDIX 3

## Moving From Paediatric to Adult Services: Wrexham Maelor Hospital Model

Transition from Paediatric to Adult Services – Wrexham Model							
Age of Young Person	16-17 years old (Age flexible where appropriate)			17-18 Years Old (Age flexible where appropriate)			
	School Year 12			School Year 13			
Location	Children's Outpatients Department Year 1			Adult Diabetes Centre/Outpatients Year 2			
Clinic	T	T1	T1a	T2	T3	T4	T5
Suggested dates	Sept	Dec	March	July	Oct	Jan	July
Department to lead Consultation	Paediatric	Paediatric	Paediatric	Paediatric - Nurse	Adult	Adult	Adult
Room 1							
Staff involved	Paediatric Consultant  PDSN	Paediatric Consultant Adult* Consultant  PDSN DSN  <i>*Young person is handed over to adult consultant at this point.</i>	Annual Review  PDSN Paediatric Dietitian  See HCP separately.  Not all people with diabetes will be seen in this clinic; depends on annual review date.	Adult* Consultant Paediatric Consultant  PDSN DSN	Adult* Consultant  PDSN DSN Clinical Psychologist	Adult* Consultant  PDSN DSN Clinical Psychologist	Adult* Consultant  PDSN DSN Clinical Psychologist  <i>Young person is handed over to DSN at this point</i>
Room 2				Room 2			
Staff involved	Paediatric Dietitian	Paediatric Dietitian  Adult Dietitian		Adult Dietitian Paediatric Dietitian	Adult Dietitian available in separate room if needed	Adult Dietitian available in separate room if needed	Adult Dietitian available in separate room if needed
Clinic Time	30min	1 hour (30 min each)	1 hour 10 min	1 hour (30 min each)	30 min (+30 min)	30min (+30 min)	30min (+30 min)
Additional Information							
<p>*The patient will see the same adult consultant and same staff that make up the young adult team through their transition clinics. Following T5 they will be invited to specific young adult clinics up until the age of 25 years.</p> <p>Where a young person is admitted to hospital, they will be admitted under the paediatric department prior to the T2 clinic and to adult departments following this clinic.</p>							

Based on service configuration in summer 2017

The Wrexham Model consists of five joint clinics that move the young person from the paediatric setting to the adult setting. The clinics are run jointly by paediatric and adult clinicians with responsibility shifting over the course of the clinical sessions. It is the same member of staff that engages with the young person each time throughout this process to ensure continuity, as is the same members of staff that they continue to see up until the age of 25. The young person is also made aware of the importance of attending these specific T1-T5 clinics, they understand that they cannot be rescheduled, and each clinic runs on two separate dates within the specific month. If they are unable to attend the first date, there is a second option.



# Moving From Paediatric to Adult Services: Prince Charles Hospital Model

## APPENDIX 4

Moving from Paediatric to Adult Services: Prince Charles Hospital, Cwm Taf UHB											
Age	16-17 years				17-18 years				Transfer to		
	Year 1				Year 2						
	T1	T2	T3		T4	T5	T6	T7			
	Spread over 5 clinics				Spread over 4 clinics				Spread over 4 clinics*		
HCPs in Clinic	Nurse Lead – PDSN <ul style="list-style-type: none"><li>Paediatric Diabetes Specialist Nurse (PDSN)</li><li>Paediatric Diabetes Specialist Dietitian</li><li>Adult Diabetes Specialist Nurse (DSN)</li></ul>				Nurse Lead – Adult DSN <ul style="list-style-type: none"><li>PDSN</li><li>DSN</li><li>Adult Diabetes Specialist Dietitian</li></ul>				Consultant Led <ul style="list-style-type: none"><li>Paediatric Consultant</li><li>Adult Consultant</li><li>Adult Diabetes Specialist Dietitian **</li><li>PDSN **</li><li>DSN **</li></ul>		Transfer to Young adult clinic or Insulin pump clinic where appropriate by 18 <sup>th</sup> Birthday
Structure of Clinics	<ul style="list-style-type: none"><li>Introduction to transitional process and getting familiar Adult DSN</li><li>Assessment of dietary habits and meal pattern</li><li>Assessment of SMBG including any difficulties</li><li>Assessment of MDI/CSII regimes including any difficulties</li><li>Assessment of CHO counting skills and imparting knowledge to beginners</li><li>Assessment of knowledge on sick day rules and hypoglycaemia</li><li>Imparting basic knowledge on managing diabetes with travel, alcohol, pregnancy and contraception and driving</li><li>CSII downloads and CGM (if needed)</li><li>Keep parents on board with proceedings</li><li>Leaflets to be provided</li></ul>				<ul style="list-style-type: none"><li>Introduction to adult dietitian</li><li>Improving skills on CHO counting and consolidating knowledge</li><li>Explore willingness to attend DAFNE</li><li>Consolidate knowledge and practise of SMBG, MDI/ CSII</li><li>Re-emphasis on knowledge and understanding of hypos, driving , travel, pregnancy etc</li><li>Downloads of CSII and BM monitoring machines</li><li>Improving knowledge on sick day rules, injection sites and set changes</li><li>Patient to be advised to contact adult DSN in difficulties , provide contacts</li><li>Keep parents on board with proceedings</li><li>Leaflets to be provided</li></ul>				<ul style="list-style-type: none"><li>Introduction to Adult consultant</li><li>Brief about running of young adult clinics and follow up arrangement</li><li>Re-assessment of knowledge learned in T1-T5</li><li>Encourage enrolment for DAFNE</li><li>Further input from adult dietitian (if needed)</li><li>Re-assessment of treatment regimes , CSII downloads and adjustment as needed</li><li>Formal hand over (via letter) and outstanding medical issues to be addressed Ongoing support from adult DSN and contacts</li><li>Transfer (after 2nd visit)</li><li>Keep parents on board during clinic visit.</li></ul>		Adult Consultant will arrange F/U in Adolescent clinic/CSII clinic as appropriate  Enrolment for DAFNE  Ongoing support from adult DSN and Adult Dietician, ensure all contacts are provided for in between appointment support.
<ul style="list-style-type: none"><li>Each patient will attend 5 Nurse led and 2 Consultant led clinics</li><li>This takes between Young Person's 16<sup>th</sup> and 18<sup>th</sup> Birthday</li><li>*Consultants will lead four clinics per year (at 3 monthly interval)</li><li>**It is favourable that PDSN / DSN / Adult Dietician attend also attend these clinics but this may not always be possible.</li></ul>											

- Each patient will attend 5 Nurse led and 2 Consultant led clinics
- This takes between Young Person's 16<sup>th</sup> and 18<sup>th</sup> Birthday
- \*Consultants will lead four clinics per year (at 3 monthly interval)
- \*\*It is favourable that PDSN / DSN / Adult Dietician attend also attend these clinics but this may not always be possible.



## APPENDIX 5

### ‘Meet the Team’ Wall at Prince Charles Hospital Diabetes Centre

The adult diabetes team at the Diabetes Centre, Prince Charles Hospital, Cwm Taf UHB have created a ‘meet the team’ wall so that anybody coming into the service from paediatric care or those who are new to the service can put a face to the name. This includes the whole team ranging from administration staff to consultants.

In addition to their name, picture and job title, the wall also provides a list of services that are available at the Diabetes Centre for people living with diabetes.



#### Services we provide

- Reviewing of your blood glucose records
- Advise of dose adjustments of insulin in person and via telephone
- Provide education on different areas of diabetes and its management
- Initiate and provide ongoing support with insulin pumps
- Advice on issues concerning diabetes and its management in relation to travel, exercise/sport, work, college/university
- Provide structured education for people with Type 1 diabetes: Dose Adjustment For Normal Eating (DAFNE) course
- Preconception/Ante-natal care
- Transitional care
- Inpatient care
- Podiatry clinics

# PHQ-9 Depression

Name: .....

Hospital No:.....

Date of completion: .....

## APPENDIX 6

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?  
(Please circle your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
<b>Column Totals:</b>				
<b>Total Score:</b>				

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.



# APPENDIX 7

## Generalized Anxiety Disorder 7-item (GAD-7) scale

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?  
(Please circle your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
<b>Add the score for each column:</b>				
<b>Total Score (add your column scores):</b>				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all \_\_\_\_\_

Somewhat difficult \_\_\_\_\_

Very difficult \_\_\_\_\_

Extremely difficult \_\_\_\_\_

Source: Spitzer RL, Kroenke K, Williams JBW, Lowe B. A brief measure for assessing generalized anxiety disorder. Arch Intern Med. 2006;166:1092-1097.

## Screening for diabetes distress

The DDS-2 is designed for use as a brief screening measure to identify individuals with diabetes distress in need of further investigation. Respondents rate 2 items on a 1-6 scale, and an average score is calculated. It is recommended that any individual with an average score over three is then asked to complete the fuller DDS (17 item version) to obtain further information on the exact nature of their distress.

## APPENDIX 8

# THE DIABETES DISTRESS SCREENING SCALE

**DIRECTIONS:** Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

DDS-2	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

Fisher, L., Glasgow, R. E., Mullan, J. T., Skaff, M. M., & Polonsky, W. H. (2008). Development of a brief diabetes distress screening instrument. *The Annals of Family Medicine*, 6(3), 246-252.

**DIRECTIONS:** Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle “1”. If it is very bothersome to you, you might circle “6”.

DDS-17	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
6. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6
7. Feeling that friends or family are not supportive enough of self-care efforts (eg planning activities that conflict with my schedule, encouraging me to eat the “wrong” foods).	1	2	3	4	5	6
8. Feeling that diabetes controls my life.	1	2	3	4	5	6
9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

Polonsky, W. H., Fisher, L., Earles, J., Dudl, R. J., Lees, J., Mullan, J., & Jackson, R. A. (2005). Assessing psychosocial distress in diabetes. *Diabetes care*, 28(3), 626-631.

## INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress scale score plus 4 sub scale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. The letter in the far right margin corresponds to that item's subscale as listed below. **We consider a mean item score of 3 or higher (moderate distress) as a level of distress worthy of clinical attention.** Place a check on the line to the far right if the mean item score is  $> 3$  to highlight an above-range value.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored 3 or higher.

Total DDS Score:

- a. Sum of 17 item scores. \_\_\_\_\_
- b. Divide by: \_\_\_\_\_ 17 \_\_\_\_\_
- c. Mean item score: \_\_\_\_\_  $\geq 3$  \_\_\_\_\_

A. Emotional Burden:

- a. Sum of 5 items (1, 3, 8, 11, 14) \_\_\_\_\_
- b. Divide by: \_\_\_\_\_ 5 \_\_\_\_\_
- c. Mean item score: \_\_\_\_\_  $\geq 3$  \_\_\_\_\_

B. Physician-related Distress:

- a. Sum of 4 items (2, 4, 9, 15) \_\_\_\_\_
- b. Divide by: \_\_\_\_\_ 4 \_\_\_\_\_
- c. Mean item score: \_\_\_\_\_  $\geq 3$  \_\_\_\_\_

C. Regimen-related Distress:

- a. Sum of 5 items (5, 6, 10, 12, 16) \_\_\_\_\_
- b. Divide by: \_\_\_\_\_ 5 \_\_\_\_\_
- c. Mean item score: \_\_\_\_\_  $\geq 3$  \_\_\_\_\_

D. Interpersonal Distress:

- a. Sum of 3 items (7, 13, 17) \_\_\_\_\_
- b. Divide by: \_\_\_\_\_ 3 \_\_\_\_\_
- c. Mean item score: \_\_\_\_\_  $\geq 3$  \_\_\_\_\_







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This standard has been written by Sara Crowley, Diabetes Transitional Care National Coordinator for NHS Wales with the help of Jon Matthias, Children and Young People's Wales Diabetes Network Manager.

This standard has been influenced by all disciplines working in diabetes care across all seven health boards in Wales including Paediatric and Adult Diabetes Consultants, Paediatric and Adult Diabetes Specialist Nurses, Paediatric and Adult Diabetes Specialist Dietitians and Clinical Psychologists. It has been further shaped by the experiences and input from young people and young adults living with diabetes themselves, their parents and families.

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With an additional thanks going to Matthew Pugh of Ginger and Tall for the document design. Comments and enquiries can be directed to [Cyp.Diabetesnetwork@wales.nhs.uk](mailto:Cyp.Diabetesnetwork@wales.nhs.uk)