

Care of Children and Young People with Diabetes West Midlands Overview Report

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CARE OF CHILDREN AND YOUNG PEOPLE WITH DIABETES

WEST MIDLANDS OVERVIEW REPORT

INTRODUCTION

- 1 During 2011 the West Midlands Paediatric Diabetes Network decided that it would like to undertake peer review visits to services across the West Midlands with the following aims:
 - To improve the quality of services
 - To improve the patient and family's experience
 - To reduce variation in the quality of services across the West Midlands

- 2 The Network and West Midlands Quality Review Service (WMQRS) set up a joint Steering Group to develop Quality Standards and oversee the review process, in accordance with WMQRS governance arrangements. Membership of this Steering Group is given in Appendix 1. The Steering Group developed draft Quality Standards which were circulated for comment across the West Midlands and finalised in June 2012. The Quality Standards are available on the WMQRS website www.wmqrns.nhs.uk and have four sections:

JA-	Primary Care
JC-	Acute Trust-Wide
JR-	Paediatric Diabetes Services
JZ-	Commissioning

- 3 Peer review visits took place between September 2012 and March 2013. This report presents an overview of the findings of these peer review visits and draws out common themes. Throughout the visits reviewers were impressed by the enthusiasm of staff and their keenness to improve care for children and young people with diabetes. Staff were often working under significant pressure but this did not detract from their determination to provide high quality care. Children, young people and their parents who met visiting teams were highly appreciative of the care they received.
- 4 Fourteen of the 15 paediatric diabetes services in the West Midlands were reviewed, with visits to all except Dudley Group NHS Foundation Trust. These review visits were run alongside the WMQRS review visits covering the care of adults with long-term conditions. Reports of each visit are available on the WMQRS website www.wmqrns.nhs.uk. Appendix 2 shows compliance with each of the Quality Standards.
- 5 Each review team comprised one or more consultant paediatric diabetologist, one or more paediatric diabetes specialist nurses (PDSN) and sometimes another NHS representative or a parent (Table 1). Fifty eight days of Continuing Professional Development was provided for NHS staff. Involvement of parents and young people as reviewers proved more difficult than expected; parents were involved in only three of the 14 review visits and no young people took part as reviewers. All reviewers who were trained were offered the opportunity to take part in a visit.

Table 1 Reviewers

Discipline	Number trained 2012	Trained in previous programmes	Took part in a review	Review days
Consultant*	19	3	15	25
Paediatric Diabetes Specialist Nurse*	17		14	26
Dietitian*	4		3	3
Psychologist	1		1	2
Commissioner	1		1	2
Manager	1	1	0	0
Parent	4		3	3
Total	47	4	38	61

* includes 1 reviewer from outside the West Midlands in each of these categories

- 6 A good practice sharing event was held on 26th June 2012 and presentations from this event are available on the WMQRS website www.wmQRS.nhs.uk

PATIENT PATHWAY

- 7 This overview will follow the patient pathway for children and young people with diabetes and then look at some of the infrastructure issues raised by the reviews. Findings were categorised as good practice (GP), for 'further consideration' (FC), concern (C) or serious concern (SC). The number of services and the categorisation of the issue will be shown in brackets, for example, (C:4) indicates that the issue was of concern in four of the 14 services reviewed.
- 8 Only 50% of the 16 primary care areas reviewed had guidelines on the identification and same day referral of children and young people with suspected diabetes. This finding chimed with the experience of several reviewers who commented on problems of delayed referrals.
- 9 Specialist advice was available from specialist teams 24/7 in 10 of the services reviewed¹ and the relevant QS was met in nine of the 13 services where ward staff were involved in the 24/7 arrangements². Some aspect of the arrangements was commented on by reviewers in eight services (C:5; FC:3), including unclear arrangements, staff being phoned when off duty, including when on holiday, and unclear guidelines. Good practice was identified at Walsall Healthcare NHS Trust and at Birmingham Children's Hospital NHS Foundation Trust. At George Eliot Hospital NHS Trust, contact details for the service were noted on each clinic letter, making it easy for families to access up to date contact details.
- 10 Daily contact for at least seven days after diagnosis and, if necessary, for two weeks was in place in 11 services³ (C:2). Information was available in all Trusts that were reviewed, however, the amount and quality of information available varied and reviewers highlighted this as an issue in some areas (C:1, FC:5). Good practice was found in three services, Wye Valley NHS Trust (Hereford), University Hospitals Coventry and Warwickshire NHS Trust and Shrewsbury and Telford Hospital NHS Trust.

¹ QS JR-204

² QS JC-502

³ QS JR-601(d)

- 11 Eight services had an appropriate policy covering links with education services⁴ with particular good practice identified in Sandwell and West Birmingham Hospitals NHS Trust, Burton Hospitals NHS Foundation Trust and Hereford.
- 12 The relevant Quality Standards for information and support for children, young people and their families were met in five services⁵, with some issues being raised, especially around the need for more structured education and self-management programmes (SC:1; C:1; FC:8). Good practice was identified in Worcestershire, where patients had access to a wide range of age and condition-specific and general self-management courses and the team had been nominated for an award for their participation in a research pilot for paediatric diabetes structured education. Good practice was also identified in Hereford, Shropshire, Coventry, Walsall, South Warwickshire NHS Foundation Trust and Burton (the 'Young Bertie' programme).
- 13 Robust arrangements for three monthly reviews were in place in 11 services and for annual reviews in six services. Good practice included the annual review template in South Warwickshire and the nursing annual review sheet in Worcestershire Acute Hospitals NHS Trust. There were no concerns about review arrangements but reviewers made suggestions for improvements in five services. Heart of England NHS Foundation Trust had a particularly good recording format for nursing clinical notes.
- 14 Seven services had formal policies covering transition to adult services⁶ with some issues being raised (C:1; FC:4) and good practice found in Coventry and Burton. Some services had arrangements in place but these were not documented in a formal policy.

INFRASTRUCTURE

- 15 Only one service had sufficient staff with appropriate competences for the usual number of children and young people for whom they were providing care. Particular shortages were of consultants (4), PDSNs (9), dietician (9), psychologist (4) and administrative support (3). Reviewers were impressed by the involvement of a youth worker in The Royal Wolverhampton NHS Trust, young people being involved in consultant appointments in Birmingham Children's Hospital and the availability of PDSNs from 8am to 8pm in University Hospital of North Staffordshire.
- 16 Only two services had a competence framework which described clearly the competences expected for roles within the service. Some Trusts had described nursing competences but not competences for other staff. In some places mandatory training, personal development plans and appraisals were in place but not linked to the needs of the paediatric diabetes service. A diabetes link nurse and appropriate ward staff training was in place in 10 services⁷.
- 17 Appropriate support services and equipment were generally available with availability of point of care testing or results being the most commonly raised issue (C:3; FC:1).
- 18 Governance arrangements were generally robust although only seven services were collecting the expected data⁸. Nine services had a rolling programme of audit (C:1; FC:2) and 12 services had appropriate arrangements for multi-disciplinary review and learning. Only seven services met the Quality Standard covering feedback and involvement of children, young people and their families⁹. Some services collected

⁴ QS JR-602

⁵ QS JR-103 5/14; JR-104 6/14; JR-107 5/14

⁶ QS JR-502

⁷ QS JC-204

⁸ QS JR-701

⁹ QS JR-199

feedback but there was no evidence that they had used this to improve the service. Mid Staffordshire NHS Foundation Trust had an active parent group which supported the feedback and involvement process.

COMMISSIONING

- 19 The introduction of *Best Practice Tariff* had clearly focussed commissioners' and providers' attention on services for children and young people with diabetes and many resulting improvements were seen during the visits. Reviewers were surprised, however, that some services and commissioners were not yet fully aware of the implications or not yet planning to meet *Best Practice Tariff* (C:2; FC:1). At least seven services were facing staffing issues or availability of HbA1c in clinics which were affecting their ability to meet *Best Practice Tariff* requirements.
- 20 Eight services did not participate in a local network¹⁰ (C:4; FC:4), and some shared adult and paediatric local networks did not provide much time for discussion of the care of children and young people. Most services attended the regional network¹¹.

EVALUATION

- 21 The 2012/13 long-term conditions and paediatric diabetes review programmes were externally evaluated by Harry Ward (Economic and Commissioning Consultancy). The 2012/13 Evaluation Report is available on the WMQRS website: www.wmQRS.nhs.uk
- 22 Key points from the evaluation were:
 - a. The training programme was well received by participants.
 - b. The preparation phase was well rated.
 - c. The conduct and organisation of the visits were positively rated by participants.
 - d. The results of the overall evaluation were broadly in line with previous years.
 - e. Response rates for evaluation forms were good for the training sessions, but still poor for the visits and improved for the overall evaluation where a web based form was used for the first time.
 - f. Twenty-two specific recommendations are made which would enable WMQRS to continue to improve the peer review process for future years.
 - g. Consideration should be given to carrying out an analysis to establish whether there is a relationship between NHS Outcome Framework metrics and compliance with WMQRS Quality Standards

¹⁰ 6/14 met QS JR 604

¹¹ 13/14 met QS JR-605

23 The following table compares the evaluation results with previous WMQRS programmes and other review programmes run by the same team.

Question	Response	%							
		Pre-WMQRS			WMQRS				
		CIC 2003	Cancer 2005	CIC 2006	Renal 2009	SC&T	2010 *	2011 **	2012 ***
Did the preparation for the visit to your own organisation lead to changes in the services provided?	Improvement or Significant Improvement	34	41	71	14	50	33	32	0
Was the peer review visit to your own organisation a helpful or unhelpful experience?	Helpful or Very Helpful	72	47	78	80	100	73	74	79
Did the report of the visit give a fair reflection of the services at your own organisation at the time of the visit?	Fair or Very Fair	83	58	65	66	100	73	68	84
Was the experience of being a reviewer useful in developing your own services?	Useful or Very Useful	81	74	89	91	92	88	80	88
Has your organisation been able to address the 'immediate risks' (if any) and 'concerns' identified in the visit report?	Addressed in full or nearly addressed		43		48	23	56	60	58
Has the peer review process overall been useful to your organisation in improving services?	Useful or Very Useful	67	45	61	52	73	73	71	60

Key

CIC Care of critically ill and injured children

SC&T Services for children and young people with sickle cell disease or Thalassaemia (2010/11 reviews)

* WMQRS 2010/11 review programme covered urgent care, critical care, stroke (acute phase) & TIA, and vascular services.

** WMQRS 2011/12 review programme covered mental health services, health services for people with learning disabilities, dementia services and care of vulnerable adults in acute hospitals.

*** WMQRS 2012/13 review programme covered care of adults with long-term conditions and the care of children and young people with diabetes.

24 Some additional evaluation questions specific to paediatric diabetes were also asked. The responses to these questions suggested that some changes had been made prior to the review visits, including revision of guidelines and updating information for children and families.

NEXT STEPS

25 Most of the issues identified by this review programme can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches. Individual organisations are responsible for taking action and monitoring progress through their usual governance mechanisms. Commissioners have responsibility for supporting quality improvement across the whole patient pathway.

APPENDIX 1 MEMBERSHIP OF STEERING GROUP

Dr Chizo Agwu	Chair Peer Review Committee	Sandwell and West Birmingham Hospitals NHS Trust
Dr John Scanlon	Consultant Paediatrician	Worcestershire Acute Hospitals NHS Trust
Lorna Rowes	Paediatric Diabetes Dietician	Sandwell and West Birmingham Hospitals NHS Trust
Lizbeth Hudson	Paediatric Diabetic Specialist Nurse	Sandwell and West Birmingham Hospitals NHS Trust
Dr Ash Reynolds	Clinical Psychologist	Black Country Partnership NHS Foundation Trust
Dr Kathryn McCrea	Consultant Paediatrician	Shrewsbury and Telford Hospitals NHS Trust
Dr Parakkal Raffeeq	Consultant Paediatrician	University Hospital of North Staffordshire NHS Trust
Hazel Malcolm	Senior Children's Commissioner	Birmingham and Solihull NHS Cluster
Dr Melanie Kershaw	Consultant Paediatric Endocrinologist	Birmingham Children's Hospital NHS Foundation Trust
Gill Salt	Paediatric Diabetes Nurse	The Royal Wolverhampton NHS Trust
Lesley Drummond	Clinical Nurse Specialist/Diabetes Home Care Coordinator	Birmingham Children's Hospital NHS Foundation Trust
Emma Day		Birmingham Children's Hospital NHS Foundation Trust
Jane Eminson	Acting Director	West Midlands Quality Review Service
Sarah Broomhead	Quality Manager	West Midlands Quality Review Service
Sue McIldowie	Long Term Conditions Programme Support	West Midlands Quality Review Service

APPENDIX 2 COMPLIANCE WITH QUALITY STANDARDS

Ref	Quality Standard – Short Title	Met	Not met	N/A	Total	% met
Primary Care						
JA-298	Primary Care Development Programme	8	8	0	16	50
JA-502	Primary Care Referral Guidelines – Diabetes in Children	8	8	0	16	50
JA-605	Sharps Disposal	16	0	0	16	100
Acute Trust-wide						
JC-203	Board Level Lead for Care of Children	13	1	0	14	93
JC-204	Paediatric Ward Link Nurse and Staff Training	11	3	0	14	78
JC-502	24/7 Advice – Paediatric Diabetes	9	4	1	14	64
JC-606	Trust-wide Group: Diabetes in Children	5	9	0	14	36
Paediatric Diabetes Services						
JR-101	General Support for Patients and Carers	10	4	0	14	71
JR-102	Service Information	12	2	0	14	86
JR-103	Condition-Specific Information	5	9	0	14	36
JR-104	Personal Care Record	6	8	0	14	43
JR-105	Three Monthly Review	11	3	0	14	79
JR-106	Annual Review	6	8	0	14	43
JR-107	Education and Self-Management Programmes	5	9	0	14	36
JR-199	Involving Young People and Families	7	7	0	14	50
JR-201	Lead Consultant and Lead Nurse	14	0	0	14	100
JR-202	Staffing Levels and Skill Mix	1	13	0	14	7
JR-203	Competence Framework and Training Plan	2	12	0	14	14
JR-204	24/7 Advice - Diabetes	10	4	0	14	71
JR-299	Administrative and Clerical Support	6	8	0	14	43
JR-301	Support Services	12	2	0	14	86
JR-302	Pathology Services	9	5	0	14	64
JR-401	Facilities and Equipment	13	1	0	14	93
JR-402	IT System	9	5	0	14	64
JR-501	Clinical Guidelines – Diabetes in Children	11	3	0	14	79
JR-502	Transition	7	7	0	14	50
JR-601	Operational Policy	3	11	0	14	21
JR-602	Education of Children with Diabetes	8	6	0	14	57
JR-603	High Dependency Care for Children with Diabetes	13	0	0	13	100
JR-604	Local Network Attendance	6	8	0	14	43
JR-605	Regional Network Attendance	13	1	0	14	93
JR-699	Primary Care Training and Development	10	4	0	14	71
JR-701	Data Collection	7	7	0	14	50

Ref	Quality Standard – Short Title	Met	Not met	N/A	Total	% met
JR-702	Audit	9	5	0	14	64
JR-798	Review and Learning	12	2	0	14	86
JR-799	Document Control	7	7	0	14	50
Commissioning						
JZ-298	Primary Care Development Programme	10	8	0	18	56
JZ-604	Commissioning: Diabetes in Children	9	9	0	18	50
JZ-605	Education of Children with Diabetes	8	10	0	18	44
JZ-707	Local Network	6	12	0	18	33
JZ-708	Needs Assessment	6	12	0	18	33
JZ-709	Strategy	2	16	0	18	11
JZ-710	Quality Monitoring – Paediatric Diabetes Services	6	12	0	18	33