

## Special Report

# Diabetes specialist nurses and role evolution: a survey by Diabetes UK and ABCD of specialist diabetes services 2007

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### Abstract

**Aims** To review the working practices of UK diabetes specialist nurses (DSNs), specific clinical roles, and to examine changes since 2000.

**Methods** Postal questionnaires were sent to lead DSNs from all identifiable UK diabetes centres ( $n = 361$ ). Quantitative and qualitative data were collected on the specific clinical roles, employment, and continual professional development of hospital and community DSNs, Nurse Consultants and Diabetes Healthcare Assistants.

**Results** 159 centres (44%) returned questionnaires. 78% and 76% of DSNs plan and deliver education sessions compared with 13% in 2000 with a wider range of topics and with less input from medical staff. 22% of DSNs have a formal role in diabetes research compared with 48% in 2000. 49% of Hospital DSNs, 56% of Community DSNs and 66% of Nurse Consultants are involved in prescribing. 55% of DSNs carry out pump training, 72% participate in ante-natal and 27% renal clinics. 90% of services have independent diabetes nurse-led clinics. 93% of services have a dedicated Paediatric DSN. The mean number of children under the care of each PDSN is 109 (mode 120), which exceeds Royal College of Nursing recommendations. 48% of DSNs have protected time for continuing professional development of staff and 15% have a protected budget. One third of DSNs are on short-term contracts funded by external sources.

**Conclusions** The DSN role has evolved since 2000 to include complex service provision and responsibilities including specialist clinics, education of healthcare professionals and patients. The lack of substantive contracts and protected study leave may compromise these roles in the future.

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**Keywords** clinical care, diabetes specialist nurses, role development, service fragmentation

**Abbreviations** ABCD, Association of British Clinical Diabetologists; DSN, Diabetes specialist nurse; PDSN, Paediatric diabetes specialist nurse

### Introduction

The diabetes specialist nurse (DSN) role exists to educate and support people living with diabetes and their families at all stages in their lives [1]. The role, first introduced over 60 years ago,

became more common in the 1980s with the advent of differing strengths of insulin and the introduction of self-monitoring of blood glucose [2]. There were 1278 DSNs working in the UK in 2007 in either the primary or secondary care setting or both [3].

The role of the DSN within the multidisciplinary diabetes team has continued to evolve as diabetes care has changed in response to patient demand as well as the Working Time Directive [4] and Government policies and strategies such as The NHS Plan [5] and the National Framework for Diabetes [6]. The necessity for this

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change was acknowledged in the 2000 Association of British Clinical Diabetologists (ABCD) survey of secondary care services for diabetes in the UK [7]. This survey, which included an investigation of DSN roles and responsibilities, predicted that DSN roles would undergo significant change as a result of changes set out in the NHS Plan, and that these roles would continue to evolve to include more direct responsibility for diabetes clinical management and nurse prescribing.

Given the speed of change within the NHS, Diabetes UK and ABCD considered that it was important that the independent views of specialists involved in diabetes service provision were sought, and commissioned a second series of surveys to review diabetes services throughout the UK in 2007. An integral part of this work was this diabetes specialist nurse survey, the aims and objective of which were to explore the working practices of UK DSNs, specific clinical roles and examine changes since 2000.

## Methods

A questionnaire was developed by the Diabetes UK and ABCD Specialist Services Study Group. The survey comprised 80 open and closed questions to examine the organization of provision of diabetes services relating to hospital and community DSNs, Nurse Consultants in Diabetes and Diabetes Healthcare Assistants including Diabetes Care Technicians. The questionnaire included sections on specific clinical roles, prescribing behaviour, paediatric nursing, education and research, employment data, pay banding and continual professional development.

The questionnaire was piloted by a group of in-patient and primary care-based DSNs, and questions that were confusing or poorly answered were amended accordingly. The full survey was carried out between February and December 2007.

Paper questionnaires were mailed to 361 primary and acute diabetes services as listed in internal and external databases including Binley's Directory of NHS Management, 2006, the Diabetes UK internal professional membership list and the Diabetes Inpatient Specialist Nurses membership list.

The lead DSN from each locality was invited to complete the survey. The first question was designed to examine whether the local service was operated across primary and specialist services. Where services were not integrated, the recipient was asked to copy the questionnaire to obtain responses from both primary and specialist services.

The questionnaire was posted in February 2007 and replies collected until December 2007. A second questionnaire and reminder was sent to all non-responders after 1 month, followed by telephone calls to the centre concerned in order to maximize the final response rate.

## Data process

The completed questionnaires were collated and data entered onto a database designed to assist with data entry (SNAP; SNAP

Solutions LLC, Evanston, IL, USA) and later exported into the Statistical Package for Social Sciences (SPSS; SPSS Inc., Chicago, IL, USA).

Localities providing responses to both 2000 and 2007 surveys were identified to compare trends in service provision between this sub-sample and the complete sample of respondents in both surveys.

## Statistical analysis

The results were analysed using Excel and SPSS using parametric and non-parametric tests according to the distribution of the data. Association and correlation between variables were measured by Pearson's  $r$  or Spearman's  $\rho$  and chi-square tests. One-way ANOVA was used to assess variance between means. A  $P$ -value of  $< 0.05$  was considered statistically significant. Data are presented as frequencies, medians and ranges. Open-ended questions were systematically coded by one of the research team (C.G.), using an approach based on the framework method. Each response was read and assigned a code and grouped into themes that emerged from the data.

Data are presented as percentages, with the actual number of responders in parentheses.

## Results

One hundred and fifty-nine responses were received, representing a 44% response rate. Of responders, 18% (28) were from primary care organizations, 81% (129) from acute trusts and 1% (two) from nurses working in specific general practice surgeries.

Seventy-five percent (119) of responses were from England, 9% (15) from Northern Ireland, 8% (12) from Scotland and 6% (10) from Wales. In addition, there were three responses from the Channel Islands and the Isle of Man. Sixty-five percent (100) reported they operated within a service that spanned primary and secondary care service.

Trusts in the South of England were more likely to report an integrated service than the rest of England ( $P = 0.019$ ) and there was a trend towards national differences between the four nations (Scotland 91%, Northern Ireland 79%, England 62% and Wales 40%,  $P = 0.059$ ).

Where services were not integrated, 76% (41) of respondents were based in specialist services and 24% (13) in primary care. Five did not respond to this question.

## Clinical roles

Virtually all DSNs (315, 95%) were involved in some aspect of patient management, although this varied according to the role. Overall, two-thirds of services offered patients a named nurse contact with no difference between hospital (63%) and community DSNs (69%).

Hospital DSNs were more likely than community DSNs to undertake specialist clinics such as pre-assessment clinics prior to surgery ( $P < 0.000$ ), ante-natal ( $P < 0.000$ ), renal

**Table 1** Specific roles undertaken by diabetes specialist nurses (DSN)

	Hospital DSN [(N = 132), %]	Community DSN [(N = 104), %]	Paediatric DSN [(N = 67), %]	Nurse Consultant in diabetes [(N = 29), %]	P
Patient management	99	96	93	76	
Prescribing	49	56	27	66	
Non-medical prescribing	47	46	9	55	
Dose adjustment only	68	62	63	17	
Pump training*	55	36	43	21	0.003
Hypertension clinic*	22	11	5	21	0.019
CVD	30	20	3	28	
Foot clinics*	34	14	2	10	0.000
Renal clinics*	27	9	2	14	0.000
In-patient work*	98	36	54	24	0.000
Ante-natal clinics*	72	41	12	35	
Pre-assessment clinics prior to surgery*	23	5	0	7	0.000
Education for nursing staff*	98	89	88	90	0.007
Education for medical staff*	92	81	73	76	0.008
Education for other allied healthcare professionals	91	91	70	79	
Education for patients	93	95	75	76	

\*Significant differences between hospital DSN and community DSN.

( $P < 0.000$ ), foot clinics ( $P < 0.000$ ) and pump training ( $P = 0.003$ ).

Eleven percent of DSNs undertook roles other than diabetes such as general medicine and endocrinology compared with 8% of DSNs in 2000.

Ninety percent of services offered separate clinics where the nurses worked without immediate medical supervision, whereas in 2000 this role was not identified. The type of clinical work undertaken in nurse-led clinics was diverse and complex (Table 1). The mean number of weekly independent clinics provided in each centre was 3.3 (median 4, range 0 to > 4).

Of hospital-based services, 71% provided a telephone help-line available to all patients. Thirty-three percent offered a paediatric telephone help-line and 27% had a dedicated pregnancy telephone service, whereas 16% offered telephone access to other specific patient groups. Of those with a telephone

service, 91% offered this during weekday office hours, but only 12% offered the service 24 hourly 7 days a week. Five percent operated a weekday evenings service and 2% a weekend office hours service. Most (94%) of the help-lines were operated by hospital DSNs, but the help-line was also manned by secretaries (11%), education centre staff (5%) and other staff including junior doctors. There are no data concerning help-line services operated by primary care staff.

### Nurse prescribing

Although 77% of trusts had one or more nurses who had attended a nurse prescribing course, nurse prescribing was undertaken in only 48% of responding trusts (Table 2). The reasons for this difference included delayed implementation and lack of approval for trust protocols and formulary.

**Table 2** Comparison data of role components 2000/2007 surveys

	Overall			Comparable hospitals		
	2007	2000	P value	2007	2000	P value
	Percentage	Percentage		Percentage	Percentage	
Patient management	99.2	97	NS	98.7	100	NS
Prescribing	48.5	31	0.002	53.9	31	0.02
Dose adjustment only	68.2	77	NS	60.7	76	0.03
Education for nursing staff	97.7	98	NS	98.7	98	NS
Education for medical staff	92.4			93.4		
Education for other allied healthcare professionals	90.9			90.8		
Patient education	93.9			93.4		

As the indicators for education are not comparable, we were not able to check for significant differences.

**Table 3** Topics covered in education sessions

	Percentage 2007 (N = 151)	Percentage 2000 (N = 183)	P
Nature of diabetes	99	99	
Why metabolic control is important	95	97	
Impact of diet and exercise	95	97	
Coping with diabetes during illness	94	98	
Hypoglycaemia	94		
Driving	93	94	
Home blood monitoring*	90	98	0.002
Travel	89	91	
Insurance	89	92	
Employment	89	86	
Smoking	88		
Footwear*	87	76	0.008
Injection technique*	86	97	0.000
<i>Carbohydrate dose adjustment</i>	83		
Prescription charges	81	83	
Contraception	76	81	
<i>Pre-conception counselling</i>	74		
Erectile dysfunction	71		
Home urine monitoring*	44	73	0.000
<i>Group initiation of insulin</i>	41		
<i>Intensive insulin therapy</i>	22		
Other	15		

\*Significant differences. Italics indicate new topics introduced since 2000.

### Paediatric nursing

Ninety-three percent (113) of services had a dedicated PDSN, of whom 97% had a paediatric nursing qualification. The mean number of children per PDSN was  $109 \pm 7$  (mode 120), which exceeds the Royal College of Nursing (RCN) recommendation of one whole-time equivalent PDSN for 70 children with diabetes [8]. The number of dedicated PDSNs in most services was one (121 respondents), with only 38% of services having two or more. There was a wide variation in the provision of dedicated PDSNs. For example, in one service there was only one 0.4 whole-time equivalent unqualified PDSN for a caseload of 270 children.

### Diabetes education provision

Most DSNs and Nurse Consultants were involved in diabetes education provision for both healthcare professionals and patients. Education for healthcare professionals was provided by 94% (132) of hospital DSNs, 87% (104) of community DSNs,

82% (29) of Nurse Consultants and 76% (67) of Paediatric DSNs.

Ninety-seven percent of services provided patient education sessions in both primary care and secondary care locations. The majority (97%) offered sessions on weekdays, but 19% also held sessions in the evenings and 4% at weekends.

Structured education sessions for people with Type 1 and Type 2 diabetes were commonly available with around 85% (115) providing National Institute for Clinical Excellence (NICE)-approved programmes [9]. There were no significant regional differences in the provision of structured education sessions. Patient education sessions covered a broader range of topics than were identified in the 2000 survey. New topics included pre-conceptual counselling (74%), carbohydrate counting and dose adjustment (82%), smoking cessation (88%) and erectile dysfunction (71%) (Table 3).

### Research

One in five nurses had a formal role in diabetes research (22%) compared with 48% in 2000 ( $P < 0.000$ ).

### Employment data

Acute trusts employed the majority of hospital DSNs (95%), Health Care Assistants and Diabetes Care Technicians (63%). Primary care organizations employed most of the community DSNs. Nurse Consultants were employed and managed by both types of organization: 48% (14) were employed by primary care, 38% (11) by the acute trust, 3% (1) by both and 10% (3) by another organization. Thirty-three percent [8] were managed by the acute trust, 54% (13) by primary care organizations, 4% (one) by both and 13% (three) by another organization.

Approximately one in five trusts did not have a written job description for the role of the hospital DSN. One-third of responders identified DSNs on short-term contracts funded by external sources.

### Locality of employment

The locality of work varied depending on who employed the DSNs. DSNs employed by secondary care worked mainly in hospital wards and out-patient departments, whereas one-third reported DSNs working across hospital and primary care. Hospital and community DSNs employed by Primary Care Organizations worked mainly in primary care, although nearly half of the community DSNs worked in both the hospital and community setting. General practice-employed DSNs tended to work wholly in primary care.

Only 35% of hospital DSNs employed by acute trusts and 44% of community DSNs employed by the primary care provider worked in both hospital and community settings. This is a significant reduction compared with 2000, when 85% of nurses worked across both the hospital and community. These findings are consistent with results obtained from services

involved in both the 2000 and 2007 surveys. In this sub-group, 91% of the 2000 comparable services worked in both settings compared with only 30% in 2007 ( $P < 0.000$ ). The nature of service integration was a common theme reported by DSNs and was described in both positive and negative terms. The dimensions of the theme ranged from changes over time, being a costed activity and how collaborative working had developed. Comments received included:

‘We all used to work together as a team, now very separate and less communication if any’

‘The Acute Trust don’t allow community cross over unless paid for’

‘Poor integration with acute trust, inpatients discharged’

‘Twice monthly multi-disciplinary team across primary and secondary care’

Specific service level agreements for diabetes services were reported by 56% of responders.

### DSN grading

Most nurses had been banded according to the new pay structure set out by Agenda for Change. There were no significant differences between the mean numbers of nurses in each band by region.

### Continuing professional development of staff

Forty-eight percent (73) had protected time for the continuing professional development (CPD) of staff, but only 15% (22) had a protected CPD budget. This varied regionally; those in the South of England (27%) were more likely to have protected funding for training than DSNs in the North (9%) or Midlands (5%,  $P = 0.013$ ).

## Discussion

This UK survey of diabetes nurses has demonstrated the diverse and expanding role of the DSN over the last 8 years and the integral role that nurses have in the clinical care of people with diabetes and within the multidisciplinary diabetes team. DSNs are now taking on more complex aspects of clinical care and education that would previously have been undertaken by doctors. In addition, there has been the creation of diabetes care technicians, who have adopted some of the roles seen as traditional parts of the DSN role. This diversification of role should be seen as a positive step forward in response to the changing needs of people with diabetes and the changing NHS. Indeed, the development of the DSN roles was predicted by the 2000 ABCD survey.

At the same time, we are witnessing a fragmentation of services, with fewer nurses working in both primary and secondary care settings, which threatens the ability of the health service to provide high-quality integrated services. Furthermore, there are a large number of nurses who are on short-term externally funded contracts, which may hamper the

retention of skills in diabetes services when these contracts expire. The lack of time and resources dedicated to CPD and research is worrying at a time when many new and more complex treatments are becoming available.

There have been many changes in the role of DSNs since their inception 60 years ago and it is likely that these changes will continue. There has been a widening of the clinical role, which now includes responsibilities for nurse prescribing, pre-assessment clinics, ante-natal, renal, foot clinics and pump training. More nurses are working independently, as shown by the frequency of nurse-led clinics.

DSNs have also adopted new working practices to meet the changing demands of people with diabetes. Most services offer telephone help-lines that are manned by DSNs.

As the work of DSNs has become more complex to meet the challenge of new therapies and technologies and the move to integrated diabetes care, two new roles have emerged. The role of Nurse Consultants with strong leadership and clinical skills was predicted in the 2000 survey. These posts were expected to evolve from senior hospital DSN roles, but in practice the Nurse Consultant role has been adopted by both primary and acute trusts, with more Nurse Consultants working in primary care.

What was not predicted was the creation of the Diabetes Health Care Assistant or Diabetes Care Technician role. This role has developed in response to the need for a wider skill mix in diabetes care and incorporates competencies aligned to the diabetes annual review. This role would more commonly be expected to be placed in primary care, where many of the annual reviews are now undertaken; however, the majority of these are based in acute care.

These new roles have led to the development of a new career structure for diabetes nursing and have supported the shift by DSNs towards increasing specialization in diabetes management.

The number of paediatric DSNs (PDSN) working entirely with children with diabetes has greatly increased, with only six services (5%) in 2007 reporting no separate PDSN compared with 41% in 2000. Although there has been clear expansion of this role, it still falls short of the levels recommended by the RCN. There is marked variation in provision between hospitals, and some services appear particularly stretched with large case loads per nurse.

In addition to the expanding roles, DSNs play an increasingly crucial role in patient and healthcare professional education. Although there is still a multidisciplinary approach to course planning, it is often the DSN who leads the planning and delivery of education programmes. The programmes have also become more sophisticated following the NICE guidance to introduce approved structured education. Given this additional complexity, it is reassuring that so many services now offer these programmes.

At the same time as these new developments and initiatives, Agenda for Change was being implemented to assess pay and conditions. Following this, a survey of DSNs by Diabetes UK in 2007 revealed considerable variation in grading and responsibilities [10]. Although the Agenda for Change process

appears to have reduced geographical differences in pay as highlighted in the 2000 survey, almost one-fifth of nurses banded by 2007 had no job description on which to base pay bands. This suggests that some DSNs may have been banded accorded to generic group job descriptions. It is therefore unlikely that the new expert clinical roles being taken on by DSNs are being recognized in terms of pay progression. This, coupled with a number of barriers to role progression, may lead to frustration with these issues.

The innovation in nurse prescribing has been impeded by trusts failing to provide pathways to facilitate this new skill. Furthermore, specialist knowledge and skills need to be underpinned by continual professional development. It is concerning that 40% and 45%, respectively, of DSNs reported that study leave time had been reduced and funding requests denied. Access to study leave or funding has not improved in recent times, with still only one-half of DSNs having protected time and only 15% having protected CPD budgets. The successful integration of DSNs into advanced clinical care is in danger of being undermined further by lack of commitment to support nurse engagement in research.

One-third of hospital DSNs and community DSNs are employed on short-term contracts, funded by external sources. This lack of long-term job security may further affect recruitment and retention of highly skilled specialist nurses.

Access to high-quality integrated care at the right time by the right person for people with diabetes is a central tenet of both ABCD and Diabetes UK. There is evidence that since 2000 there has been a fragmentation of services. In 2000, diabetes specialist services were characterized by cross-boundary working of diabetes nurses. Since then, there has been significant splitting of services between primary and secondary care settings. This is contrary to the concept of integrated care, and the long-term effect it will have on the diabetes nursing profession and care of people living with diabetes remains to be seen.

There are a number of limitations to the survey. Overall the response rate was only 44% and therefore there is a possibility of responder bias. There are important differences between this survey and the previous ABCD survey in 2000. In 2000, the answers were completed by Consultants answering on the nurses' behalf and therefore may not be directly comparable. Nevertheless, when the results of those trusts that took part in both surveys were analysed separately, there was no change in the findings, suggesting that the results are representative of services at both time points. A further limitation of the survey is that questions were not asked about the competencies and qualifications required to be a DSN.

In summary, the diabetes specialist role has expanded and developed to meet the needs of the ever-growing diabetes population and government directives. There has been considerable progress over the last 8 years since the previous survey. The lack of opportunity for study leave and research opportunities is concerning. This, coupled with lack of long-term job security, may affect the retention and recruitment of DSNs in future years. It may also be that DSN training and education

needs to be underpinned by a formal training curriculum, as suggested in the 2000 survey. Fundamental changes that have led to services developing separately in primary and secondary settings may affect the continuity of patient care.

A number of recommendations follow the findings of the survey. In order to facilitate best practice in the care of people with diabetes, it is essential that DSNs have protected access and funding to continual professional development in the form of study leave and through participation in research activities. The case-load of existing PDSNs should be reduced to the levels recommended by the RCN to improve care of children and young people with diabetes.

Having developed a career structure for DSNs, it is vital this is enabled through accurate job descriptions on which to base pay and that job security is supported through permanent contracts.

In order to promote and facilitate the ethos of integrated diabetes care, DSNs should have the opportunity to meet regularly with their peers, whether working in primary or secondary care.

## Competing interests

J.J. and C.G. have none to declare; R.I.G.H. is an Honorary Consultant Diabetologist working in the NHS.

## References

- 1 Castledine G. *The Role of the Diabetes Specialist Nurse*. Royal College of Nursing (RCN) Nursing Forum Presentation in RCN and Diabetes Specialist Nursing Working Party Report, 1989. London: RCN, 1991.
- 2 Davies M, Dixon S, Currie CJ, Davis RE, Peters JR. Evaluation of a hospital diabetes specialist nursing service: a randomised controlled trial. *Diabet Med* 2001; **18**: 301–307.
- 3 CMA Medical Data. *The Directory of Diabetes Care*. Loughborough: CMA Medical Data, 2008.
- 4 British Medical Association. European Working Time Directive (EWTD): Background. *BMJ* 2006. Available at <http://www.bma.org.uk/ap.nsf/content/ewtdbkgrd> Last accessed 9 August 2007.
- 5 Department of Health. *The NHS Plan: A Plan for Investment. A Plan for Reform*. London: Department of Health, 2001.
- 6 Department of Health. *National Service Frameworks for Diabetes: Standards*. London: Department of Health, 2001.
- 7 Winocour PH, Ford M, Ainsworth A, on behalf of the Association of British Clinical Diabetologists. Association of British Clinical Diabetologists (ABCD), Survey of specialist diabetes care services in the UK, 2000. 2. Workforce issues, roles and responsibilities of diabetes specialist nurses. *Diabet Med* 2002; **19**(Suppl. 4): 27–31.
- 8 Royal College of Nursing. *Paediatric and Diabetes Adolescent Group at the Royal College of Nursing. Specialist Nursing Services for Children and Young People With Diabetes*. London: RCN, 2006.
- 9 National Institute for Clinical Health and Excellence. *Guidance for the Use of Patient Education Models for Diabetes*. Technology appraisal 60. London: NICE. Available at [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0009/78687/003015.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0009/78687/003015.pdf) Last accessed 8 November 2008.
- 10 James J, Gosden C, Holt RIG. Agenda for Change and NHS reconfiguration: effects on diabetes service provision and impact on diabetes service delivery and patient care. *Pract Diabetes Int* 2007; **24**: 247–251.