

# Whose diabetes is it anyway?

## Lindsay Oliver

Consultant Dietitian and National Director for Year of Care Partnerships, Year of Care office, Wansbeck General Hospital, Ashington, UK

### Correspondence to:

Lindsay Oliver, Consultant Dietitian and National Director for Year of Care Partnerships, Year of Care office, Wansbeck General Hospital, Woodhorn Lane, Ashington NE63 9JJ, UK; email: Lindsay.oliver@nhct.nhs.uk

This paper was presented as the 2017 Janet Kinson lecture at the 2017 Diabetes UK Annual Professional Conference held in Manchester, UK

**Janet Kinson practised as a Diabetes Specialist Nurse in Birmingham and demonstrated a remarkable commitment to diabetes education by developing a programme to support what was then the newly-emerging profession of diabetes specialist nursing. She was forward thinking and saw the potential to do things differently, but insisted on high quality.**

**As the nominated speaker for the Janet Kinson lecture I want to reflect upon my own experiences of working in diabetes and of some important changes that have happened over the last 25 years based on an ethos and value system which is fundamentally patient centred.**

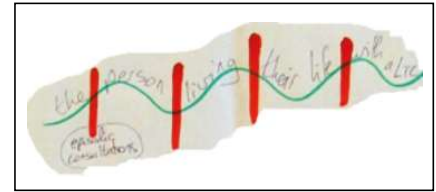
The three themes in my lecture are:

- The contribution and sometimes overlooked resource of the dietitian within the diabetes team.
- The untapped potential of the person with diabetes and the importance of supporting them to develop the knowledge, skills and confidence to live well with their diabetes.
- The importance of systematic high-quality services designed around the needs of the individual.

If we consider the perspective of an individual with a long-term condition such as diabetes (Figure 1), it reminds us that all of the important activity to manage and look after diabetes takes places outwith the 20–30-minute, two to three times a year consultation (Figure 1: orange lines). And yet, as health care professionals, we sometimes expect that these regular visits to clinics will be enough to enable the person to manage their own health, claiming credit when people do ‘well’ and throwing our arms up in despair when targets aren’t being achieved. In reality, we aren’t in charge, we have a relatively limited role in managing diabetes, and outcomes are by and large driven by the person.

### Changing role and contribution of dietitians within diabetes care

I qualified as a dietitian in 1989 with a keen interest in diabetes, and I wanted to make a difference. However, I found my early career hugely frustrating because at that



**Figure 1.** Living with a long-term condition – as depicted by a patient with diabetes; orange lines represent episodic consultations. (© Year of Care)

time there were no specialist diabetes posts and dietetics was usually delivered separately from the rest of diabetes care, with very little clinical information to draw upon to support decision making or to feed back to the person. People were sent to the dietitian as a form of punishment and as a last resort. I certainly didn’t feel valued and I can’t imagine the people who used the service found it as useful as it could be. It didn’t really utilise any of the knowledge or skills I had spent four years learning at university.

For me this all came to a head when I arrived at a general practice clinic and was faced by a receptionist who had forgotten I was coming and hadn’t booked a clinic room. She showed me to the cleaning cupboard! I felt I might leave dietetics altogether. However, in 1994 I went for an interview at North Tyneside for a newly-created diabetes specialist dietitian post – one of the first of its kind. The post had been created following a local (unpublished) study which had developed a new role called a ‘Diabetes Advisor’. In the study, people with type 2 diabetes had been randomised to ongoing care with a nurse or a dietitian which turned out to be equally effective and acceptable to patients. Interestingly, the funding for this study had been obtained from Kellogg’s since the usual sources of research funding felt it unethical to allow dietitians to be responsible for individual patient care.

### Northumbria diabetes service

It was here that I met Dr Sue Roberts, who has been an inspiration to me and to so many people who have worked alongside her. The service she developed was

unique and there were always opportunities to challenge the way things were done. There was a strong focus on organised and systematic care, with good links between primary and specialist care, facilitated by training and close working relationships. There were clear pathways; everyone knew their role and how things worked and we spent time examining data, reflecting on practice and tending to our training needs. The philosophy, principles and aims of the service were clear and written down (Figure 2). Every year we went to the local lighthouse and had a productive awayday.

It was also an effective service, and I suspect one of the first examples of a properly integrated diabetes service. In 2004, one of the local GPs published data from the comprehensive diabetes register, which demonstrated that the outcomes across the whole population were as good as the intensively-controlled arm of the UKPDS trial.<sup>1</sup> However, this was achieved with significantly less weight gain than expected. In our model of care, not only were dietitians seeing people and supporting lifestyle change, they were also supporting and up-skilling general practice staff in diabetes while keeping the specialist service appraised of what was happening in routine primary care.

The team of nurses, doctors, podiatrists, physiologists and administrators were committed and passionate about what they did. What really stood out was the way the team talked about and related to patients, with a huge amount of respect for the way they chose to manage their lives. We tried to use psychological rationale to understand behaviours and health beliefs to help us best know how to support people. I learnt a new phrase – unconditional positive regard.

This was exemplified by the training and support we received from our psychologists: Dr Peter James and Dr Yvonne Doherty. They trained the whole team to understand and deliver much more psychologically-informed services and consultations. This wasn't just about motivational interviewing. We all had to develop new ways of consulting with people and a whole host of

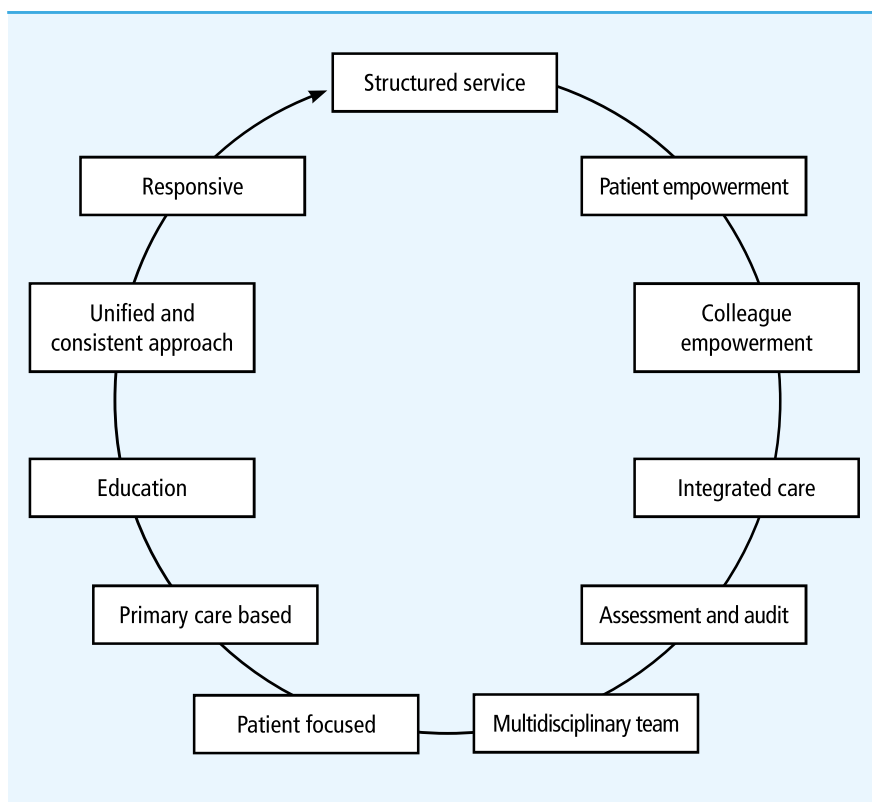


Figure 2. The principles of Northumbria Diabetes Service

methods to maintain positive therapeutic relationships with patients and to challenge and support different ways of thinking.

Working in this way has cemented for me the critical nature of high-quality consultation and communication skills within diabetes and long-term conditions care. This is demonstrated in our local Dove Data which show a strong association between patient involvement, good glycaemic outcomes and lower costs for prescribing.

### Developing the dietitian's role at Northumbria

Perhaps as a result of this environment, I began to think about people who were starting insulin and the local and national data that showed people weren't seeing the improvements they expected. It's a huge step for someone to make the transition to an injectable therapy and so, if it doesn't work, it reduces their confidence in making a difference to their own outcomes. It also diminishes their trust and relationship with the diabetes team.

So I led the trial of a very structured approach which we called a 'pre-insulin assessment'. This

included a detailed assessment, giving consistent messages and information about choices, leading to a plan to maximise all current therapy (lifestyle and medication). At the same time, we learnt about the concerns the individual might have about current and future treatment – a form of supported shared decision making. The impact was clear – only 50% of people needed to start insulin and, for those who did, glycaemic goals were achieved with much less weight gain than predicted.<sup>2,3</sup> This is now part of our routine care pathway for people with type 2 diabetes. Our dietitians make decisions to directly refer people to groups or 1:1 injectable starts, avoiding unnecessary appointments and delays and freeing up space in outpatient clinics for people who really need to see a consultant. This was developed in specialist care but now happens in general practice and has become a 'next steps assessment' due to the broader range of therapeutic options now available.

The next steps assessment is an example of several dietetically-led initiatives which have improved the outcomes and involvement of those with diabetes in our patch – our

expertise is about food, but we integrate that into discussions about other diabetes treatments and medicines and psychological approaches which are, in turn, integrated into the rest of routine diabetes care.

The dietitians at Northumbria:

- Offer one-to-one support to people in a supportive manner with no hint of punishment or 'telling off'.
- See people in clinics who traditionally would see medics or nurses in other settings – completing an entire review, but with a focus on food and lifestyle choices.
- Work across primary and specialist care and share our learning from both perspectives.
- Lead on aspects of care pathways as the key professional at certain points in a person's journey.
- Lead on new ways of working, such as patient education programmes, and have developed other initiatives such as effective weight management programmes.

As a result of leading on this, I became the first consultant diabetes dietitian. This is all in stark contrast to my beginnings as a newly-qualified dietitian (trying to avoid the cleaning cupboard!), but it does demonstrate that dietitians can make a huge contribution to the overall work in diabetes and how important it is to ensure this sometimes underutilised groups of professionals are integrated into routine diabetes care and given the chance to develop and lead.

We now have 10 whole-time-equivalent dietitians working across primary and specialist care, and the team continues to develop new effective approaches based on our learning. One of these, which had a huge impact on our professional group, was structured patient education, starting with DAFNE.

### Structured patient education DAFNE

At the time, we were first looking at the intensified insulin programme developed by Michael Berger's team in Germany; carbohydrate counting had been assigned to the dusty shelves of history. At that point, carbohydrate counting was associated with very restrictive, inflexible diets in which a daily prescription of carbohydrate was made up from a fairly

limited 'exchange' list. These diets were not in keeping with nutritional guidelines for the general population. As a result, the dietetic profession had shunned the approach and instead focused on qualitative dietary regimens (low glycaemic index and healthy eating). In addition, the food messages for both type 1 and type 2 diabetes were the same.

The Dusseldorf team had demonstrated that their programme supported people to achieve clinically-significant improvements in glycaemic control without an increase in severe hypoglycaemia.<sup>4</sup> Our visiting team from King's, Sheffield and Northumbria observed their type 1 training programme, which focused entirely on counting carbohydrate and insulin dose adjustment to achieve both flexibility and better clinical outcomes. We were amazed at how well it worked. On our return, although we were very enthusiastic, the dietetic profession was unsure and took a lot of persuading and retraining to take on the approach. Carbohydrate counting is now the acknowledged dietary strategy and evidence-based practice in terms of nutritional therapy in type 1 diabetes and is recommended in all national and international guidelines.<sup>5</sup>

DAFNE was accepted by professionals because we were able to use the UK feasibility study to show that it improves glycaemic outcomes without a deterioration in weight and cardiovascular risk.<sup>6</sup> It also improves quality of life, and has subsequently been shown to reduce unplanned health care utilisation.<sup>7</sup> However, what makes DAFNE important to me is that it gives people with diabetes the knowledge, skills and confidence to manage their diabetes on a day-by-day basis. And so, overall, DAFNE has had a much broader impact; it has:

- Legitimised the role of dietitians in type 1 diabetes.
- Changed core messages around type 1 diabetes treatment ('insulin as the treatment') – recognising the role of carbohydrate counting – differentiated from messages in type 2.
- Led the way in rolling out a complex educational intervention with associated training, standards and quality assurance to maintain fidelity to the original programme.

### DESMOND

I was asked to join a kick-off meeting for type 2 structured education and was keen to use my experience from DAFNE to support people with type 2 diabetes. At a local level we wanted to retain a high-quality approach but the numbers of those with type 2 diabetes were increasing significantly. In developing the DESMOND programme, we were particularly aware of the impact of health beliefs and behaviour change in the management of type 2 diabetes. We therefore focused on a patient-centred philosophy and underpinning psychological theories. The programme uses an approach in which people are given information and are supported to make their own decisions around goals and actions in order to manage their own diabetes.<sup>8</sup>

From a service point of view, we embraced DESMOND as it fitted entirely with our ethos and we also saw how it could help in terms of sustainability as the incidence of diabetes went up.<sup>9</sup> It is now embedded in our local pathway, with good uptake. At a local level we continue to support DESMOND as it:

- Achieves biomedical measure outcomes akin to our best general practices.
- Achieves greater weight loss and increased likelihood of giving up smoking.
- Leads to significant change in health beliefs including people feeling they understand their diabetes more, knowing that it is 'serious', but with a feeling that they can do something about it.
- In terms of health care cost, the only thing that is less expensive is a year's supply of metformin.

### The importance of quality assurance

In the same way that Janet Kinson had applied rigorous standards to the training of diabetes nurses, both the DESMOND and DAFNE group felt that the same principles should apply to the development and roll-out of structured education. In order to do this we developed rigorous methods of training and quality assuring the programmes. In my role as chair of the DAFNE educator group, I worked alongside a strong

team who developed a train-the-trainer and quality assurance process for educators and DAFNE courses.<sup>10</sup> This was supported by the development of national guidelines for structured education.<sup>11</sup>

Sadly, the importance of standards in education is still not accepted everywhere. We would never prescribe half doses of medication; it is still common practice to deliver education programmes which do not meet national standards and have no evidence. From a personal perspective I find it hard to believe that my daughter has had more hours of driving lessons than my nephew, who has type 1 diabetes, has received in education about how to manage his diabetes.

## Care and support planning and Year of Care

North Tyneside joined the Year of Care programme in 2007. I was keen to get involved as it seemed to fit with the ethos and values of our diabetes service, and also seemed the next logical step to support people who have attended structured education. I had also seen at first hand the impact of Quality and Outcomes Framework on the behaviours and attitudes of professionals towards people with diabetes. In some instances, the focus on ticking boxes seemed to dominate the need to develop good therapeutic relationships with patients. It felt as if the focus had shifted away from supporting people with their diabetes and talking about their concerns, health beliefs or ideas. I saw the Year of Care approach as a means to address this. I am now the National Director for this programme and our small team of trainers, clinical leads and programme managers has worked with a significant number of organisations to provide support, training and practical tools to implement this approach in primary and specialist care.

### What is Year of Care?

If you consider the perspective of a person living with a long-term condition, highlighted in Figure 1, it emphasises the significance of the person being in the driving seat of their own care, with a need for the system and the professions within it to support the person to be in charge of their own health and wellbeing.

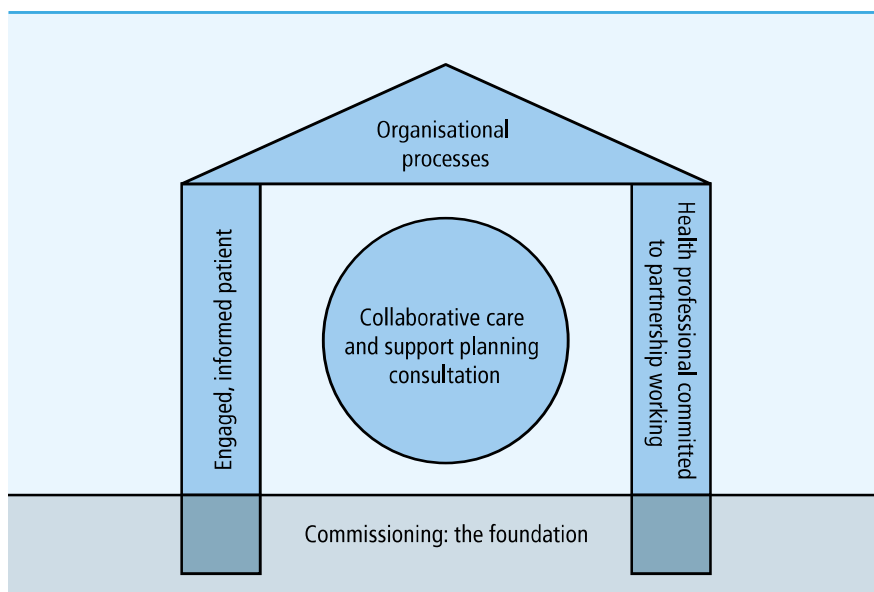


Figure 3. The Year of Care house (© Year of Care)

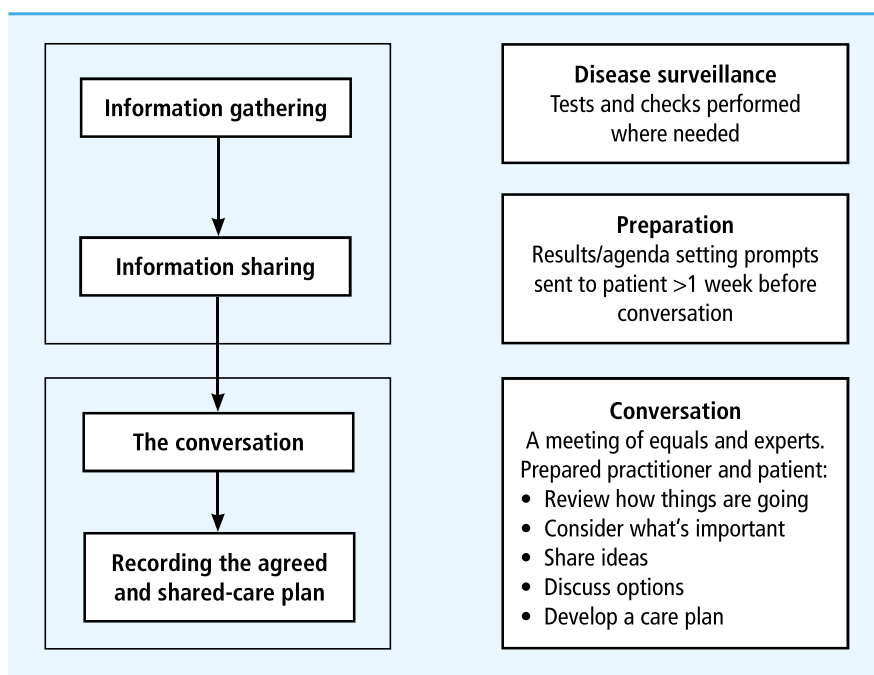


Figure 4. The care and support planning process. (© Year of Care)

The Year of Care approach was designed with people living with diabetes who wanted to get more out of the time they spend with health care professionals.

The approach introduces care and support planning and links with support for self-management. This is enabled by a change in how care is organised and through training of health care professionals. The changes that need to take place at both a practice and system level are detailed in the Year of Care house (Figure 3).

Care and support planning requires a redesign of the traditional annual review, splitting it into a two-step process (Figure 4). This involves an initial disease surveillance review with a trained health care assistant (where all care processes are completed in a single appointment) and then a conversation a few weeks later focused entirely on involving and supporting the individual.<sup>12</sup> The whole process is enabled by the sharing of information with the patient between the disease surveillance

**About 'Preparation'**

- '...you can't take it in when they talk to you... this way you can take your time.'
- '...helped me see what was happening and so I knew what to ask.'
- '...it's 100% better than being told "no action necessary".'
- '...helped me raise issues I was worried about.'
- '...talking about something you know about rather than something you're kept in the dark about.'

**About the 'Conversation'**

- '...I could ask the questions instead of being asked the questions...'
- '...interested in what I had to say.'
- '...I could talk about what was important to me.'
- '...talking with me rather than looking at the computer.'
- '...you may not have all the answers but you've helped me work things out.'

**Box 1.** Comments from people who have experienced care and support planning

review and the care and support planning conversation.

One of the key differences with this approach is the introduction of information sharing where agenda-setting prompts and routine results are shared with the person with diabetes before their care and support planning conversation. While some practitioners can be sceptical about this additional step, people with diabetes and other long-term conditions find this really helpful and feel it makes them more equal to the health care professional during the care and support planning conversation. It saves time, helps people see what is happening and reminds us all about who these results actually belong to. Some of the comments from people with diabetes who have experienced care and support planning are shown in Box 1.

The purpose of changing the process is to create the space for a more useful conversation for the person with a focus on planning. People find it a completely different experience and it supports their understanding of their condition.

The impact has been positive in terms of how valuable it feels for both the staff involved and the individuals with diabetes. It has improved care process completion and has improved outcomes. However, not all health care professionals find these new conversations easy and our training and support programme aims to help with this. The approach is now being used for many other conditions, including those relating to people who live with multiple long-term conditions.

**Summary**

I have learnt some key lessons as I have tried to develop my role and that of my dietetic colleagues, while considering how best to go about supporting people with diabetes. These apply at a number of levels and are exemplified in the Year of Care house (Figure 3). The house needs all elements to be embedded and happening systematically, with care delivery and systems designed with the focus of people with diabetes as the central care givers.<sup>13</sup>

If we think about 'whose diabetes it is', we are more likely to design and deliver services which recognise that individuals with diabetes take on most of the actions that can deliver better outcomes in diabetes.

This can therefore be supported by activities around the left-hand wall of the house (engaged, informed patient) with routine implementation of high-quality care and support planning so that people can have better conversations about their health. Education should be embedded into core care pathways and throughout the patient's journey. We should also be aware that support and activities embedded in communities can have a profound impact on how people live well with their diabetes.

For health care professionals (right-hand wall of the house), all of our effort and activities should be geared towards supporting the person to understand and manage their diabetes. Having a patient-centred philosophy of care and good communication skills is as important as being up to date with the evidence base. Teams need to

work together and squeeze out the contribution of all team members.

Creating systems (the roof and the foundation of the house) that support improving the knowledge, skills, confidence and motivation of people with diabetes to live their lives and manage their conditions will make the biggest difference to health care. Outcomes ultimately depend on the individual; however, our systems of care and quality of care can be barriers or enablers. The most important people in a service are those with diabetes and so our systems of care need to be designed around the central role that people with diabetes play in managing their own care.

**References**

1. Whitford DL, *et al.* Sustainability and effectiveness of comprehensive diabetes care to a district population. *Diabet Med* 2004;21(11):1221–8.
2. Oliver L. Outcomes for people with type 2 diabetes on maximum tolerated oral therapy who have pre-insulin assessment with a dietitian. Diabetes UK Conference 2009. Poster.
3. Forrest C, *et al.* Is weight gain inevitable when starting on insulin? (A prospective review of group starts and follow up for people with type 2 diabetes). Diabetes UK Conference 2012. Poster.
4. Mühlhauser I, *et al.* Bicentric evaluation of a teaching and treatment programme for type 1 (insulin dependent) diabetic patients: improvement of metabolic control and other measures of diabetes care for up to 22 months. *Diabetologia* 1983;25(6):470–6.
5. Dyson PA, *et al.* Diabetes UK evidence-based nutrition guidelines for the prevention and management of diabetes. *Diabet Med* 2011;28(11):1282–8.
6. DAFNE Study Group. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. *BMJ* 2002;325:746–52.
7. Elliot J, *et al.* Substantial reductions in the number of diabetic ketoacidosis and severe hypoglycaemia episodes requiring emergency treatment lead to reduced costs after structured education in adults with type 1 diabetes. *Diabet Med* 2014;31(7):847–53.
8. Davies MJ, *et al.*; on behalf of the DESMOND Collaborative. Effectiveness of a structured group education programme on individuals newly diagnosed with type 2 diabetes: a cluster randomised controlled trial of the DESMOND programme. *BMJ* 2008;336:491–6.
9. Skinner TC, *et al.* Diabetes education and self-management for ongoing and newly diagnosed (DESMOND): process modelling of pilot study. *Patient Educ Couns* 2006;64:369–77.
10. Oliver L, Thompson G. The DAFNE Collaborative: Experiences of developing and delivering an evidenced based quality assured programme for people with type 1 diabetes. *Pract Diabetes Int* 2009;26(9):371–7.
11. Department of Health, Diabetes UK. *Structured patient education in diabetes: Report from the Patient Education Working Group.* London: DoH, 2005.
12. Doherty Y, *et al.* Year of Care: key drivers and theoretical basis for a new approach in diabetes. *Pract Diabetes* 2012;29(5):183–6a.
13. Roberts S, *et al.*; on behalf of the national Year of Care for diabetes programme. Care Planning in the Year of Care Programme: Making it easier to do the right things. Diabetes UK Annual Professional Conference 2010. Poster 211.