National Assembly for Wales
Health and Social Care Committee

Inquiry into the implementation of the National Service Framework for diabetes in Wales and its future direction

June 2013

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales

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The Committee was established on 22 June 2011 with a remit to examine legislation and hold the Welsh Government to account by scrutinising expenditure, administration and policy matters encompassing: the physical, mental and public health of the people of Wales, including the social care system.

Current Committee membership

Vaughan Gething (Chair)
Welsh Labour
Cardiff South and Penarth

Rebecca Evans
Welsh Labour
Mid and West Wales

William Graham
Welsh Conservatives
South Wales East

Elin Jones
Plaid Cymru
Ceredigion

Darren Millar
Welsh Conservatives
Clwyd West

Lynne Neagle
Welsh Labour
Torfaen

Gwyn R Price
Welsh Labour
Islwyn

Ken Skates
Welsh Labour
Clwyd South

Lindsay Whittle
Plaid Cymru
South Wales East

Kirsty Williams
Welsh Liberal Democrats
Brecon and Radnorshire

Mick Antoniw and Mark Drakeford were also members during the period of the inquiry.

Mick Antoniw
Welsh Labour
Pontypridd

Mark Drakeford
Welsh Labour
Cardiff West

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Chair's foreword

Diabetes can legitimately be described as an epidemic across Wales and the rest of the UK. Diabetics make up 5% of the population and 15%-20% of hospital inpatients. The numbers of people with type 2 diabetes continues to rise and they do so at an even younger age. This is not a fringe issue. It is a major challenge for us all, not only for people working in the NHS who care for people with diabetes. The rising demand and cost of treatment is something that affects us all.

The main focus of this report is the treatment and management of diabetes in Wales. The diabetes National Service Framework (NSF) programme was established in 2003. Its mission was to set national standards, improve service quality and tackle variations in care over 10 years. We highlight some of the progress that has been made and the challenges that remain as the Welsh Government refreshes its strategy.

We have difficult continuing challenges to face about the lifestyle choices that are driving a rise in diabetes. The same lifestyle choices impact upon many public health challenges that we face. Changing our collective behaviour is not easy but it is hard not see a wider change in behaviour and choices as anything less than essential.

Our work has been informed by a wide variety of people with different experiences of managing and treating diabetes. I want to thank each person who submitted written evidence or gave oral evidence to the committee. Without the engagement and interest that the inquiry received we would not be in a position to properly scrutinise progress and recommend areas where action is required.

We look forward to receiving the Welsh Government's response to this report and hearing from the wider public on whether the report can and will help to make a difference.

Vaughan Gething AM
Chair of the Health and Social Care Committee
June 2013

The Committee's recommendations

Recommendation 1. We recommend that the Welsh Government should ensure implementation of the National Service Framework through strengthened oversight and monitoring arrangements, as a priority in the forthcoming delivery plan. We believe this should include a national leadership post to coordinate health boards' progress in delivering the NSF, and to facilitate the sharing of experiences and good practice between health boards. (Page 17)

Recommendation 2. We welcome the forthcoming delivery plan for diabetes, and recommend that the Welsh Government commits to taking appropriate action should health boards fail to deliver the services outlined in the plan. (Page 17)

Recommendation 3. We recommend that the forthcoming delivery plan should include a requirement for all GP practices to participate in the National Diabetes Audit. (Page 18)

Recommendation 4. We recommend that the Welsh Government's delivery plan should require that all diabetes patients are offered all 9 key annual health checks, and that health boards' performance in meeting this requirement should be monitored through full participation in the National Diabetes Audit. (Page 20)

Recommendation 5. We recommend that the forthcoming diabetes delivery plan should ensure that local Diabetes Planning and Delivery Groups' relationships with health boards are formalised. Health Boards should demonstrate how they take account of DPDG recommendations and fully engage with their work. Arrangements should be put in place to adopt a national approach for DPDGs, to include national terms of reference for their operation and a requirement to meet with each other to share best practice. (Page 24)

Recommendation 6. We recommend that the introduction of an integrated diabetes patient management system should be a priority for the Welsh Government. We note the commitment already made to introduce such a system, and recommend that a clear timetable for its introduction is included in the forthcoming diabetes delivery plan. (Page 27)

Recommendation 7. We recommend that future public health campaigns on diabetes should reflect the need to raise awareness of the risk factors associated with – and the early symptoms of - diabetes. (Page 31)

Recommendation 8. We recommend that the Welsh Government and health boards work together to expand the role of pharmacies in conducting risk assessments, to help improve early identification of people with diabetes. Pharmacies should also play a direct role in future public health campaigns. We believe the Welsh Government should specifically consider the value of including the HbA1c test for existing patients as an enhanced service as part of the Community Pharmacy Contractual Framework.(Page 33)

Recommendation 9. We recommend that the Welsh Government should urgently address the variances in the provision of structured education for people with diabetes. The forthcoming delivery plan should require all health boards to provide NICE-compliant structured education programmes and ensure equality of access to appropriate, timely education for all patients across Wales. (Page 37)

Recommendation 10. We believe that insulin pump therapy and the necessary accompanying education should be available to all suitable candidates to improve their quality of life. We recommend that the Welsh Government's forthcoming delivery plan include a requirement to improve the availability of education and training on the use of insulin pumps. (Page 40)

Recommendation 11. We recommend that the ThinkGlucose programme should be introduced in all health boards across Wales. (Page 44)

Recommendation 12. We recommend that the Welsh Government undertake an audit of the number of diabetes specialist nurses in post across Wales, and the proportion of their time spent on general duties. The Welsh Government should consider the merits of issuing guidance to health boards on recommended numbers of diabetes nurses per head of population. (Page 47)

Recommendation 13. We recommend that the Welsh Government monitors the capacity of the Diabetic Retinopathy Screening Service to provide annual checks for diabetic patients as the growing prevalence of diabetes increases demand for the service. (Page 50)

Introduction

Prevalence of diabetes

1. Diabetes is a chronic disease found in two major forms: Type 1 and Type 2. According to Diabetes UK Cymru there are more than 160,000 diagnosed diabetes sufferers in Wales - equating to 5% of the population. Additionally, an estimated 350,000 more people have pre-diabetes, which is higher than normal blood glucose levels.[1] If not properly treated, diabetes can lead to heart disease, stroke, blindness, kidney failure and foot ulceration leading to amputation.[2]

2. Type 1 is the rarer of the two diabetes forms; in Wales approximately 10 per cent of people diagnosed with diabetes suffer from Type 1. It is characterised by the destruction of the insulin producing β-cells of the pancreas by the body's own immune system. β-cell destruction results in an inability of the pancreas to produce insulin, allowing glucose to build up in the blood. It mostly develops in children, young people, and young adults.

3. Approximately 90 per cent of people with diabetes have Type 2, which can be linked to lifestyle factors such as being overweight or obese, lack of exercise and eating an unhealthy diet. Symptoms develop when the body does not respond properly to the presence of insulin (insulin resistance), and is sometimes combined with a deficiency in absolute insulin levels. It is most commonly diagnosed in adults over the age of 40 years, although it is increasingly found in children and young adults.[3]

4. Figures from Diabetes UK Cymru also show that there has been a significant and consistent increase in the prevalence of diabetes in recent years. There have been approximately 7,000 new cases annually in Wales equating to a 5% annual increase. Increases in Type 2 diabetes are attributed to an ageing population and rapidly rising numbers of overweight and obese people. The rise in the number of people with diabetes is not unique to Wales; the World Health Organisation has predicted that by 2025, the number of people with Type 2 diabetes will have doubled since 1995.[4]

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[1] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 11 – Diabetes UK Cymru*

[2] Diabetes UK, *Diabetes in the UK 2010: Key statistics on* diabetes, March 2010 [accessed 02 July 2012]

[3] Diabetes UK, *Diabetes in Wales* [accessed 03 July 2012]

[4] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 11 – Diabetes UK Cymru*

5. Research led by Professor Craig Currie at Cardiff University School of Medicine demonstrates that there has been an increase in the number of younger people diagnosed with Type 2 diabetes over recent years. His article, The incidence of type 2 diabetes in the United Kingdom from 1991 to 2010, published in May 2013, shows that the percentage of patients diagnosed on or before 40 years of age has increased from 5.5% between 1991 – 1995 to 10.3% between 2006 – 2010 among men, and that the figure for women has risen from 6.4% to 14.15% during the same time.

Cost of diabetes to the NHS

6. Poorly managed diabetes is associated with serious complications that contribute a substantial financial cost to diabetes care. While 5% of the population have diabetes, people with diabetes account for 15 – 20% of hospital inpatients and are more likely to require longer stays in hospital and be treated for more complex conditions. People with diabetes are more likely to develop cardiovascular disease, kidney disease, blindness or require amputation.[5]

7. Diabetes is a chronic condition and with people being diagnosed at a younger age, maybe in their 30s or 40s, the NHS is faced with the cost of providing their treatment for the rest of their lives. Diabetes costs the NHS in Wales £500 million each year, which is 10% of its total budget. Diabetes UK Cymru estimates that the cost could reach £1 billion by 2025 should the condition continue to rise at its current rate. They told the Committee that the largest proportion of the money spent on diabetes services, between 80-87%, covers complications associated with the disease; approximately 7% is spent on medication, with the cost of medications rising and newer therapies approved by NICE set to significantly increase medication costs further.[6]

The National Service Framework on Diabetes

8. The National Service Framework (NSF) programme was established to improve services by setting national standards to drive up service quality and tackle variations in care. Each NSF sets national standards, identifies the interventions and actions that will help meet those standards and the milestones against which NHS performance will be measured.[7]

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[5] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 11 – Diabetes UK Cymru*

[6] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 11 – Diabetes UK Cymru*

[7] Welsh Government, *National Service Framework for Diabetes (Wales) Standards* [accessed 03 July 2012]

9. In March 2003 the Welsh Government published *A National Service Framework for Diabetes in Wales – Delivery Strategy*, a 10 year plan designed to 'tackle the increasing prevalence of the condition, improve services and maximise outcomes for those diagnosed with diabetes'.[8] It set out milestones, performance management arrangements, the actions to be taken by local health boards (LHBs) and social care systems and the underpinning programmes to support local delivery. In its written evidence, Diabetes UK Cymru said that the NSF had remained the core document for diabetes planning and service delivery since its development. Despite early progress, Diabetes UK Cymru told the Committee that it had not been possible to ascertain the progress made by health boards in meeting the targets set out in the NSF in more recent years.[9]

10. In evidence to the Committee, the Welsh Government referred to a DiabetesDelivery Plan to direct and guide health board activity for the period up to 2016. It said that the plan would set out new Welsh Government commitments to the public for diabetes care in Wales and would support the delivery of service standards set out in the Diabetes NSF. The Diabetes Delivery Plan was issued for consultation on 21 December 2012.

11. In this inquiry, the Committee has gaged the views of a range of stakeholders on the progress made in implementing the NSF across health boards and its adequacy and effectiveness in preventing and treating diabetes in Wales. We also sought views on potential future actions which are required to drive this agenda forward. We would like to thank all of those who contributed to the Committee's inquiry, especially those who gave oral evidence to us in November 2012.

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[8] Welsh Government, *National Service Framework for Diabetes in Wales – Delivery Strategy*, March 2003 [accessed 29 June 2012]

[9] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 11 – Diabetes UK Cymru*

1. Implementation of the National Service Framework for Diabetes

12. When it was established in 2003, the National Service Framework (NSF) for Diabetes set out 12 standards to improve and standardise diabetes services and care throughout Wales. The aim of the NSF was to meet all 12 standards by 2013. The Committee heard that that health boards would not be in a position to meet the 12 standards by 2013.[10]

13. Dai Williams, Director of Diabetes UK Cymru told the Committee that despite the merits of the NSF itself, the lack of management and co-ordination of progress was a barrier to its success. He told the Committee:

> "When I read the NSF, I thought that it was a great document and that it was really working. So, where was the problem? The problem came when I tried to work out who was responsible for overseeing the NSF. In England, there was a diabetes lead. In Scotland, there was a diabetes lead. In Wales, there was nobody."[11]

National leadership and co-ordination

14. The Committee heard that leadership at a national level was a major barrier to health boards meeting the standards of the NSF. Concern was raised by representatives from Diabetes UK Cymru and the Diabetes National Service Advisory Group that the post of Lead Co-ordinator for Diabetes and Vascular Disease, a central post within the Welsh Government, had remained vacant since the previous post-holder had left in 2009. The written evidence from Diabetes UK Cymru stated that the Lead Co-ordinator was responsible for diabetes services at a national level and for the assessment of NSF progress, the provision of advice and co-ordination of work across health boards.[12] Dai Williams told the Committee:

> "The role of a clinical lead, essentially, is to make sure that the 12 standards of the NSF are being progressed in a logical manner and are being project-managed effectively across Wales. That is exactly what the clinical leads do in Scotland and England."[13]

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[10] National Assembly for Wales, Health and Social Care Committee, *RoP [para 15 & 39]*, 15 November 2012

[11] National Assembly for Wales, Health and Social Care Committee, *RoP [para 5]*, 15 November 2012

[12] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 11 – Diabetes UK Cymru*

[13] National Assembly for Wales, Health and Social Care Committee, *RoP [para 10]*, 15 November 2012

15. He went on to tell the Committee of the importance of the co-ordination aspect of the role of clinical need, especially in sharing best practice between health boards. He said that without such co-ordination, health boards were not aware of initiatives being developed by others to improve patient care:

> "I see the clinical lead sharing that information and coming up with a strategy to make sure that it is developed, based on evidence of how it works and so on, and passed on to other health boards to show that good practice is being shared. At the moment, health boards seem to stand by themselves with no co-ordination. I would see the clinical lead facilitating that."[14]

16. Jason Harding, Policy Manager for Diabetes UK Cymru pointed towards the clinical leads in place in Scotland and England as examples of good practice of how the role could function. He told the Committee that:

> "If you look at England and Scotland, and particularly at the clinical lead there, you will see that one of the key roles that they seem to provide is a co-ordination function. Scotland has looked at the key standards that they are trying to deliver in their action plan, and that role co-ordinates a range of sub-groups and task and finish groups to look at each of those specific areas and manages the process...In England, the diabetes lead, Dr Rowan Hillson, also works very closely with an organisation called NHS Diabetes to look to see how to manage and co-ordinate functions. So, in England, it is not just the clinical lead; there is an organisation in place to try to share best practice, to look at the National Institute for Health and Clinical Excellence guidance that is provided, and to ensure that the new clinical commissioning groups are rolling that out properly. We have a real vacuum in Wales."[15]

17. Dai Williams emphasised his view that the management and co-ordination aspects of a diabetes clinical lead position were the most important parts of such a role. He said:

> "My personal view is that a project manager and a co-ordinator are required above and beyond a clinician."[16]

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[14] National Assembly for Wales, Health and Social Care Committee, *RoP [para 10]*, 15 November 2012

[15] Ibid, *RoP [para 16]*, 15 November 2012

[16] Ibid, *RoP [para 22]*, 15 November 2012

18. The lack of a central post to co-ordinate the implementation of the NSF was also emphasised by the Diabetes and Endocrinology National Specialist Advisory Group (NSAG) as a barrier to progress. In their written evidence, the NSAG said:

> "As a consequence there has been no single person with the required knowledge whose primary responsibility is to co-ordinate all matters pertaining to diabetes within Welsh Government."

19. Their written evidence also stated that the Group had advised the Welsh Government of the importance of the role prior to the termination of the post and several times since. These views were also highlighted by members of the NSAG during their oral evidence session. Dr Phil Evans, Chair of the NSAG told the Committee:

> "The third point that we have raised is the need for a central co-ordinator for diabetes services in Government to work with Government departments, with the diabetes planning and delivery groups and with the health boards across the service to enable the co-ordination and delivery of integrated services in Wales."[17]

20. Dr David Millar Jones from Diabetes Research Network Wales also emphasised to the Committee the importance of a central co-ordinator in facilitating the exchange of good practice between the Diabetes Planning and Delivery Groups (DPDG) in each health board, a function which Diabetes UK Cymru had taken onboard itself:

> "It is quite sad in one respect that Diabetes UK, a charity, came up with the idea of getting all the DPDG leads together to exchange good practice. Surely a service such as that should be led by one co-ordinator ... unless each of the areas of good practice can talk, we will never get a good co-ordinated service. The big problem with diabetes across Wales is that provision is patchy."[18]

Assessment of progress

21. From the evidence it received, it was not clear to the Committee how much progress had been made in implementing the standards of the NSF, however witnesses were sure that the target of implementing the 12 standards by 2013 would not be met.

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[17] National Assembly for Wales, Health and Social Care Committee, *RoP [para 10]*, 29 November 2012

[18] Ibid, *RoP [para 25]*, 29 November 2012

22. Witnesses from Diabetes UK Cymru told the Committee that whilst health boards had provided data to the Welsh Government, a failure to assess that data and provide any feedback had left the health boards unaware of whether they had been making any progress in implementing the NSF targets. Dai Williams said:

> "The health boards have been feeding information back to the Welsh Government for some time. It is quite detailed information about their progress in individual health boards and processes et cetera, but they have received little or no feedback since 2009 from the Assembly."[19]

23. It was Jason Harding's view that the lack of assessment of data also stemmed from the failure to replace the Lead Co-ordinator for Diabetes and Vascular Disease, when the post became vacant in 2009. He told the Committee:

> "Within the evidence that we have provided, we have shown that there was a system in place until 2009. There was a specific role in the Welsh Government of a cardiovascular and diabetes lead. That role fulfilled a range of functions, but one of its key functions was to act as the recipient of information from the different health boards, which were reporting on a quarterly basis on their national service framework, to reflect on that information and to assess where work was being done constructively and positively and to acknowledge that, but also to identify where work was not being delivered to the standards and the expectations and then to communicate back to the health boards with action to rectify that and to provide an oversight function."[20]

24. Dr Phil Evans told the Committee that the NSAG had developed a self-assessment tool which was being used by health boards to measure progress against the NSF standards, however he shared the view that there had been no feedback on progress since 2009. He told the Committee:

> "The last time we had a collation of the national picture of the national service framework was when Mrs Helen Husband was a co-ordinator for diabetes in 2009. Ultimately, since then, we have had the self-assessment tool results, which have been going in…I am not

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[19] National Assembly for Wales, Health and Social Care Committee, *RoP [para 11]*, 15 November 2012

[20] Ibid, *RoP [para 42]*, 15 November 2012

> aware of any feedback to the health boards on the national service framework based on those reports."[21]

25. According to its written evidence, Diabetes UK Cymru undertook an exercise in Spring 2012, whereby it collated health boards' self-assessment data and produced individual reports for each health board as well as a collated report which was submitted to the Minister for Health and Social Services. Their evidence said that 'the reports demonstrated that all health boards were struggling with significant aspects of the NSF, and that a number of areas required a national approach if they were to be dealt with effectively'.[22]

26. BMA Cymru's written evidence stated:

> "It appears that data collection mechanisms do exist but that no analysis in undertaken by Government, therefore the Health Boards themselves do not know how they are performing comparatively. It is also testament to the failure of Welsh Government on this matter that the third sector has had to perform its own one-off data collection and analysis of Health Board performance."[23]

27. In their oral evidence to the Committee, Welsh Government officials told us that health boards were responsible for the planning and delivery of diabetes services, and that support was available to them from the Welsh Government. They also referred to the self assessment tool for health boards to measure their progress. David Sissling, Chief Executive of NHS Wales and Director General, Health, Social Services and Children at the Welsh Government, told the Committee:

> "Ownership of delivery of high standards of diabetes care sits with the health boards—they are responsible for the planning and delivery of care. However, we, as the Welsh Government have a very important role in ensuring that the standards, at all points, are monitored and improved, that delivery is monitored and that we provide support and, where appropriate, intervention to allow them to pursue good paths of improvement. We have a self-assessment arrangement that is consistently applied across Wales, whereby they can hold a mirror

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[21] National Assembly for Wales, Health and Social Care Committee, *RoP [para 117 & 121]*, 29 November 2012

[22] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

[23] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB16 – BMA Cymru*

> up to themselves and ensure that they are aware of their own performance levels."[24]

28. Mr Sissling acknowledged, however, that improvements were needed to strengthen the monitoring of health boards' performance in meeting the standards, and that the Welsh Government would seek to address this issue with the introduction of its new delivery plan. He told the Committee:

> "We have audit information that provides authoritative information with national rigorous standards that allow us to say how well we are doing compared with those standards and other health systems and, within Wales, against each other. Now, we recognise that we need to strengthen some of the national approaches, which is why, in the context of the new delivery plan, we are setting up an implementation group with national leadership, chief executive leadership and all clinical leads, which will report to me to ensure that this priority area is accorded the priority that it merits."[25]

29. Dr Chris Jones, the Deputy Chief Medical Officer, added that the self-assessment tool, which included approximately 230 measures, was very comprehensive and should be monitored at health board level:

> "In 2011, we worked with our clinical colleagues to produce the self-assessment, which covers not only the NSF, but also the key measures relating to the NICE guidance that has emerged subsequently. That is a very extensive and comprehensive piece of work, which was given to the health boards last year as a tool for them to facilitate board reporting. There are 230 or so measures, some of which have sub-divided measures. That is a level of detail that is clearly more appropriate for a board to monitor than for the Welsh Government to monitor."[26]

30. Dr Jones went on to say that he believed that the NSF had been monitored sufficiently, and that improvements had been made:

> "The NSF has been monitored significantly since it was published and, as David said, there has been a great deal of improvement in all aspects of diabetes services. So, although I accept entirely that there are still some areas that have not been fully implemented, there has

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[24] National Assembly for Wales, Health and Social Care Committee, *RoP [para 235]*, 29 November 2012

[25] Ibid, *RoP [para 235]*, 29 November 2012

[26] Ibid, *RoP [para 249]*, 29 November 2012

> been an enormous improvement across public health, primary care and lots of elements of hospital-based services as well."[27]

31. Some witnesses pointed to areas of improvement in diabetes services; Dr Meurig Williams said that the NSF had resulted in a reduction in the variation in quality of care across Wales,[28] however witnesses generally felt that progress was not sufficient or that it was not possible to know the extent of progress made.[29]

Our view

32. The Committee recognises the importance of planning and delivery of services at a local level, but believes that the Welsh Government could play a more active role in monitoring the data collected by health boards and could do more to promote the exchange of good practice at a national level. Evidence from numerous witnesses supports the role of a national co-ordinator for diabetes, and past experience of such a role appears to have proven valuable.

33. As the number of people with diabetes continues to grow across Wales, the Committee believes that an over-arching role, with responsibility for monitoring provision of diabetes services and for sharing best practice and developments, would ensure consistent services and improve patient care. We welcome the Welsh Government's commitment to strengthening the monitoring of the NSF standards in its forthcoming delivery plan.

Recommendation 1: We recommend that the Welsh Government should ensure implementation of the National Service Framework through strengthened oversight and monitoring arrangements, as a priority in the forthcoming delivery plan. We believe this should include a national leadership post to coordinate health boards' progress in delivering the NSF, and to facilitate the sharing of experiences and good practice between health boards.

Recommendation 2: We welcome the forthcoming delivery plan for diabetes, and recommend that the Welsh Government commits to taking

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[27] National Assembly for Wales, Health and Social Care Committee, *RoP [para 255]*, 29 November 2012

[28] National Assembly for Wales, Health and Social Care Committee, *RoP [para 74]*, 15 November 2012

[29] National Assembly for Wales, Health and Social Care Committee, *RoP [para 39 & 75]*, 15 November 2012 and National Assembly for Wales, Health and Social Care Committee, RoP [para 6], 29 November 2012

appropriate action should health boards fail to deliver the services outlined in the plan.

National Diabetes Audit

34. The written evidence from the Welsh Government said that health boards had participated in the National Diabetes Audit (NDA) since 2007. The NDA is a large clinical audit and includes data from primary and secondary care participants to compare the delivery of diabetes care against other providers in Wales and England. The Committee heard that participation in the NDA was not an onerous task, however there was disagreement between witnesses as to the number of participants in the Audit.

35. The written evidence from the Welsh Government said that over 80% of GPs had signed up to participate in the NDA, however Dr David Minton, Neighbourhood Care Networks Lead at Aneurin Bevan Health Board, said that the number of practices from the Gwent area that participated was under 20%. He said that participation was easy; the only requirement on the practice was to give consent for the data to be accessed. Dr Minton believed that the NDA was very valuable and suggested that participation should be compulsory:

> "We simply sign a piece of paper to allow the data to be taken. Personally, I would want to see it being made compulsory and that we just pull the data out. That can be done."[30]

Our view

36. The Committee recognises the importance of primary and secondary care practices participating in the National Clinical Audit in order to get a comprehensive view of the services being offered to people with diabetes. We believe that increasing participation in the Audit would allow a more accurate picture of provision to assess the consistency of services across Wales.

Recommendation 3: We recommend that the forthcoming delivery plan should include a requirement for all GP practices to participate in the National Diabetes Audit.

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[30] National Assembly for Wales, Health and Social Care Committee, *RoP [para 68]*, 21 November 2012

2. Primary care

Nine key care processes

37. Standards 10, 11 and 12 of the National Service Framework are concerned with the detection and management of long-term complications. Diabetes patients should receive nine key checks or 'care processes' from their GP at an annual review of their diabetes management.[31] These include urine and blood tests for kidney function, measurements of weight, blood pressure, smoking status, blood glucose level, cholesterol level, and tests to assess whether the eyes and feet have been damaged by diabetes.

38. Diabetes UK Cymru's written evidence notes that, in 2010 – 11, '37.7% of people with Type 2 diabetes did not receive all of their checks and 61.4% of people with Type 1 diabetes did not receive all of their checks.'[32]

39. The *National Diabetes Audit 2010-2011* findings for Wales indicate that 60 per cent of people with diabetes had records showing that all nine checks had been completed between January 2010 and March 2011. The Audit found variation between health boards and also variation among the individual checks carried out, stating that 'some like blood pressure are done almost invariably while others like urine microalbumin and foot checks or digital eye photography are notably less frequent and more variable'. [33]

40. Evidence from BMA Cymru said that resources were required to support the increasing pressure on primary and community based services as a result of the population diagnosed with diabetes. Dr Ian Millington, representing the BMA, said:

> "Delivering on care is incredibly difficult in general practice at the moment. The work has increased exponentially, but the resources have not matched it. Most GPs do what they can... The numbers are increasing. When I qualified, we were told that 2% of the population were diabetic, of which 1% was known. We are now above 5%, and, in parts of the country with high ethnicity, it is above 10%. The

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[31] NICE, *Diabetes care improves, but patients still missing out on key tests*, June 2010 [accessed 9 November 2012]

[32] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

[33] *National Diabetes Audit 2010-2011 Report 1: Care Processes and Treatment Targets*, p29 [accessed 9 November 2012]

> resources have not matched that, and that is why they may not be getting it."[34]

41. Dr David Minton, however, did not believe that GPs did not have sufficient capacity to offer the nine key care processes to their patients, and felt that most patients were offered the checks. He told the Committee:

> "I would not necessarily agree that we have not got the time to do it. I slightly disagree with the argument that the nine tests are not being done. If we look at the nine things that need to be done, they are all being at least offered. The two tests that are probably not being done routinely and regularly are urine microalbumin testing—sending a urine sample off to look for small amounts of protein as a first marker of potential kidney disease—and retinal screening. I think that the other seven are being routinely offered."[35]

Our view

42. The Committee recognises the importance of carrying out the nine key annual health checks for diabetic patients, particularly in preventing the development of further health complications. We believe that the National Diabetes Audit can be a very useful tool to monitor how many patients are offered the health checks and highlight areas where improvements are required.

Recommendation 4: We recommend that the Welsh Government's delivery plan should require that all diabetes patients are offered all 9 key annual health checks, and that health boards' performance in meeting this requirement should be monitored through full participation in the National Diabetes Audit.

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[34] National Assembly for Wales, Health and Social Care Committee, *RoP [para 107]*, 15 November 2012

[35] National Assembly for Wales, Health and Social Care Committee, *RoP [para 67]*, 21 November 2012

3. Local Diabetes Planning and Delivery Groups

43. The National Service Framework required health boards to establish Local Diabetes Service Advisory Groups (LDSAGs) to advise on the development, monitoring and performance of local diabetes services. Following NHS Wales' reorganisation in 2009, the LDSAGs were replaced with seven Diabetes Planning and Delivery Groups (DPDGs), one for each health board area, whose purpose is 'to lead, manage and report on improvements in diabetes services'.[36]

44. Diabetes UK Cymru's evidence paper describes the membership of DPDGs as varying between health boards, but usually comprising of diabetes clinicians, specialists in related disciplines and front line staff, for example diabetes specialist nurses. Patient representatives from the local community are also involved. They noted however, that it is rare that meetings occur where all disciplines are represented:

> "If some disciplines are not represented, it is not possible to obtain an update of work in that area or ascertain how well services are meeting NSF requirements."[37]

45. In his oral evidence, Dai Williams said that the creation of DPDGs, which were to include a manager amidst the membership for the first time, initially brought a fresh enthusiasm to the groups. He went on to say, however, that the enthusiasm had dwindled later on when the feeling emerged that there was no feedback or results from its work. He argued that this, in turn, had led to poor attendance at meetings. He linked the lack of feedback to the group to the dissolving of the central co-ordinator role within the Welsh Government. He told the Committee:

> "Diabetes has complications—it is a multidisciplinary condition. You need to get the kidney people, the paediatrics folk, the public health people and the GPs to come along to have their say as to how we are implementing this. It needs to be co-ordinated. If you have five or six patients and one or two members of staff, that is not going to happen. That has been the effect. There was a loss of momentum."[38]

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[36] Welsh Government, *Diabetes* [accessed 12 November 2012]

[37] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

[38] National Assembly for Wales, Health and Social Care Committee, *RoP [para 45]*, 15 November 2012

46. The written evidence from BMA Cymru emphasised the importance of primary care's involvement in the DPDGs, noting that involvement by GPs was patchy and limited:

> "Health Boards should facilitate and support involvement of both GPs and practice nurse representatives on these groups and provide support for practices to release staff including practice nurses."[39]

47. Dr Aled Roberts, representing the Association of British Clinical Diabetologists, told the Committee that the Cardiff and Vale DPDG included multi-disciplinary representation, however he was concerned that the work of the group did not receive sufficient prominence by the management of the health board:

> "Public health, general practitioners, secondary care practitioners, dieticians and pharmacists are quite well represented on our DPDG in Cardiff, so we have quite a powerful forum, but one wonders at times who is listening...We discuss what is happening on a local basis, but we are not really involved in the strategic efforts of our health board, it seems to me."[40]

48. Dr Meurig Williams, representing the Royal College of Physicians, echoed Dr Roberts' concerns in relation to his own health board, Hywel Dda:

> "Again, we represent all the vested interests in diabetes, including a powerful patient group, but the missing link is that the management of the health board itself is not fully engaged."[41]

49. Dr David Minton told the Committee that the DPDG in Aneurin Bevan health board had found itself in a similar situation, but that structural improvements had been made recently and was hopeful that the group would be able to put its decisions to the board and get responses to them.

50. Dr Minton went on to say that one improvement that could be made was to bring together chairs or members of DPDGs to discuss developments and share best practice. He said ad-hoc meetings of this type had been facilitated by Diabetes UK Cymru, and that rolling them out on a permanent basis would add value to their work:

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[39] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB16 – BMA Cymru*

[40] National Assembly for Wales, Health and Social Care Committee, *RoP [para 94]*, 15 November 2012

[41] National Assembly for Wales, Health and Social Care Committee, *RoP [para 95]*, 15 November 2012

> "…there is currently no national meeting of chairs or members of DPDGs. Diabetes UK has tried to set this up on a couple of occasions, and it has been fairly successful when it has done so. However, to use the same phrase again, that is not 'hardwired' into the system. That will be the aspect that will allow us to start to share best practice… Once that comes together more, we would become more effective."[42]

51. Witnesses from the Diabetes and Endocrinology NSAG echoed the need for improved sharing of best practice between the different DPDGs.[43]

52. Jason Harding told the Committee that for the groups to function effectively, they required a manager to co-ordinate their work:

> "a person who is there to make the group function, to ensure that people come to the group, that the right people are represented on the group, that people are aware of the information that needs to be read before a meeting, that the meetings are co-ordinated well, that action points are taken forward after a meeting and that someone checks if those actions points are done."[44]

53. The written evidence from Diabetes UK Cymru also reported that DPDG meetings take place every three months, typically lasting for two hours, which they did not believe was sufficient:

> "A rigorous assessment of the health board's work in meeting the NSF is not possible in meetings of this duration."[45]

Our view

54. Diabetes affects an increasing number of people every year and this is likely to continue. It is clear to us that the impact of this will be felt by the NHS for years to come. We believe that the Diabetes Planning and Delivery Groups are an excellent mechanism to bring representatives from across different disciplines together to consider care for patients with the condition. The commitment shown by some members of the groups is not shared by all. We believe that improvements are needed to make them more effective.

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[42] National Assembly for Wales, Health and Social Care Committee, *RoP [para 47]*, 21 November 2012

[43] National Assembly for Wales, Health and Social Care Committee, *RoP [para 22 & 25]*, 29 November 2012

[44] National Assembly for Wales, Health and Social Care Committee, *RoP [para 48]*, 15 November 2012

[45] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

Improved co-ordination of the groups at local and national levels is essential; the meetings should serve a purpose, and members should be able to see that the recommendations that they make are being considered at a higher level.

55. It is clear to us that consistent care services are needed to support patients across Wales. We believe that the DPDGs need to work more closely to learn from experiences elsewhere, build on the work of others and share success stories. We welcome the initiative taken by Diabetes UK Cymru to bring the DPDGs together, and believe that their role can be strengthened by ensuring that such meetings continue on a permanent basis.

Recommendation 5: We recommend that the forthcoming diabetes delivery plan should ensure that local Diabetes Planning and Delivery Groups' relationships with health boards are formalised. Health Boards should demonstrate how they take account of DPDG recommendations and fully engage with their work. Arrangements should be put in place to adopt a national approach for DPDGs, to include national terms of reference for their operation and a requirement to meet with each other to share best practice.

4. Integrated diabetes services

56. The Committee heard a significant amount of evidence about the importance of collaborative working and a 'partnership approach' to the delivery of diabetes services.

57. Dr Meurig Williams, representing the Royal College of Physicians, described the integration of diabetes services as an all-important step that, largely, still needed to be taken. He identified this issue as one of his key priorities for the development of diabetes services in Wales. Dr Williams said:

> "There is some excellent practice in primary care and some very good practice in secondary care and, unfortunately, communication between the two is often lamentably lacking."[46]

58. The written evidence from the Welsh Government referred to a diabetes task and finish group, established in 2010 to look at an integrated service model for high clinical value, cost effective diabetes care across Wales. The group recommended a joint working model between primary and secondary care to provide core services to patients through community clinics and community pharmacies.[47]

Information management system

59. Diabetes UK Cymru's *State of the Nation 2012* report called for NHS Wales to adopt a single IT/data management system for people with diabetes to cover all aspects of their care. This was a key issue raised with the Committee in both written and oral evidence to this inquiry.

60. Dr Meurig Williams highlighted the importance of being able to track the care being provided to a person, whether by primary or secondary care. He said that an IT system which was able to record a person's care and make that information available to other practitioners offering care to the same person was vital. He believed that it was particularly important with a condition such as diabetes, as it resulted in people receiving treatment for a range of associated ailments in various settings. He said:

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[46] National Assembly for Wales, Health and Social Care Committee, *RoP [para 85]*, 15 November 2012

[47] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-32-12 paper 4*, 29 November 2012

> "With a chronic disease such as diabetes,…patients will inevitably, during the course of their disease, ..be moving from one part of the health sector to another, between primary and secondary care. We need communication and information systems that track that movement."[48]

61. Dr Williams referred to an integrated IT system being used in Scotland, into which data could be inserted and shared by both primary and secondary practitioners.

62. The Welsh Government's paper stated that NHS Wales Informatics Service (NWIS) was finalising plans on the development of a national integrated diabetes patient management system, which would "provide timely access to accurate, current clinical information needed for the efficient and effective management of people with diabetes, as well as effective service planning and delivery within the NHS."[49]

Our view

63. When dealing with a condition such as diabetes which requires input from practitioners across disciplines and care settings, it is vital that an accurate record is kept of a patient's treatment, and that that information is available to everyone involved in their care. An integrated IT system is essential to ensure that there's no duplication of provision or that one aspect of treatment is not compromised by another. The Committee welcomes the Welsh Government's plans for an integrated diabetes patient management system, and hopes that this will achieve the outcomes desired. This should take account of and be compatible with any other attempts to develop an IT system for shared patient information. This is not the only area of practice where access to a common patient record should improve patient outcomes. The report of our inquiry into community pharmacy highlighted similar barriers and opportunities.

64. The Diabetes Planning and Delivery Groups are in an excellent position to lead diabetes care in their health board areas. With primary and secondary care representatives on the groups, they are a key vehicle to enabling effective communication between the various elements of care provision, to ensure that patients get the care they need in the most appropriate way.

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[48] National Assembly for Wales, Health and Social Care Committee, *RoP [para 86]*, 15 November 2012

[49] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-32-12 paper 4*, 29 November 2012

Recommendation 6: We recommend that the introduction of an integrated diabetes patient management system should be a priority for the Welsh Government. We note the commitment already made to introduce such a system, and recommend that a clear timetable for its introduction is included in the forthcoming diabetes delivery plan.

5. Prevention and early identification

65. Standards 1 and 2 of the National Service Framework refer to reducing the risk of people developing Type 2 diabetes and identifying people who do not know that they have diabetes or may be at risk of developing the condition. The Committee was told that the number of people with diabetes continues to rise year on year, therefore tackling the problem at an early stage is vital to reduce incidence.

66. Witnesses agreed that making people aware of the risks associated with diabetes and carrying out simple tests to measure a person's likelihood of developing diabetes were crucial to slowing the increase and eventually to reversing the trend.

Public health campaigns

67. Written evidence from Diabetes UK Cymru said that there were an estimated 66,000 people with undiagnosed diabetes in Wales and 350,000 people with higher than normal blood glucose levels. This group, they said, had a 15 times higher likelihood of developing Type 2 diabetes than the general population. They also said that the third sector had funded public health campaigns to raise awareness in recent years, but that there were no plans for such a campaign in 2013.[50]

68. Dai Williams told the Committee that raising people's awareness that they could potentially be at risk of developing diabetes would allow them the opportunity to make adjustments to their lifestyles to prevent the onset of the condition. He believed that carrying out risk assessments was the best way to gauge whether a person had a high risk of developing diabetes, but that more needed to be done to increase the uptake of risk assessments. He said:

> "…you need to explain to people that diabetes is dangerous… they need to be aware of diabetes. There have been no public health campaigns and nothing from Public Health Wales on this. Secondly, one needs to do a basic risk assessment. This is not complicated. The risk factors include diabetes being genetically in the family, and

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[50] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

> lifestyle. There is some very good evidence for basic risk assessment, but we have not been doing it in Wales."[51]

69. Dr Sharon Hopkins, Director of Public Health at Cardiff and Vale Health Board, explained the difficulties involved in getting people to change their lifestyles, and that she would welcome more aggressive campaigns to convey key messages. She said:

> "Unless we get a real handle on some of these risk factor issues, we are always going to be chasing our tails. We know that the demands on secondary care services will be getting ever greater, as the demographics in Wales demonstrate. That is because some of the lifestyle factors are so difficult to deal with. It goes to people's choices and how they feel about what responsibility they take. It goes to options and choices and it is such a difficult issue to deal with. Unless we have a Wales-wide approach, very much bought into by our communities, it will be a difficult issue. I would say, 'Yes, please, absolutely' for much more focus, much more publicity and much more concentration."[52]

Risk assessment

70. The Committee was told that assessing people for their risk of developing diabetes was one of the most important factors in preventing the continued growth in the condition. Dai Williams told the Committee:

> "Being told that you are at risk of diabetes is not necessarily a negative matter because you get an opportunity to correct it before you are faced with the consequences of ignoring it. This will not only be effective against diabetes, but will have a huge impact on other long-term conditions. So, it is an early warning system."[53]

71. Mr Williams went on to explain that detecting diabetes before it had fully developed was beneficial not only to patients in terms of their quality of life, but also to the NHS as early detection and better management would lead to fewer complications and ultimately less cost to the health service. He said:

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[51] National Assembly for Wales, Health and Social Care Committee, *RoP [para 56]*, 15 November 2012

[52] National Assembly for Wales, Health and Social Care Committee, *RoP [para 82]*, 21 November 2012

[53] National Assembly for Wales, Health and Social Care Committee, *RoP [para 59]*, 15 November 2012

> "The bottom line is: the sooner you catch diabetes, the greater the awareness of dealing with it, because you are catching it upstream. If that means that more people have to have standard tests, which include testing blood pressure, lipids and so on, then they need those. That is much better than presenting with diabetes, receiving a diagnosis and being told that there are complications because it has been unrecognised. It is a much cheaper intervention. The earlier that people are identified and can be equipped with the skills to cope with their condition, the less problematic the complications will be. It is common sense."[54]

72. Marc Donovan, representing Alliance Boots and Community Pharmacy Wales, also concurred that risks assessments were key to the early identification of diabetes.[55]

73. Dr Meurig Williams agreed that giving those high risk people the opportunity to change their lifestyle was key to minimising their risk of developing diabetes later on, but more needed to be done to achieve this. He told the Committee:

> "We are not addressing standards 1 and 2 of the NSF. We have evidence that, if those people who are most at risk of having diabetes, with what we call pre-diabetes, are able to change their lifestyle—we have various approaches to doing this—they will reduce their risk of progressing to diabetes by 58%."[56]

Our view

74. We heard startling evidence about the increasing levels of diabetes in Wales. This can already be described as having reached epidemic levels. It is clear that the impact of this will be seen for many years to come. We believe that public health campaigns play an important role in reaching out to people and raising awareness. There is the constant challenge of how to make public health campaigns more effective with people at greatest risk, as alluded to in our report on community pharmacy services. Previous campaigns have demonstrated the high volume of people who may not be aware that their blood glucose levels are higher than average, but carrying

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[54] National Assembly for Wales, Health and Social Care Committee, *RoP [para 69]*, 15 November 2012

[55] National Assembly for Wales, Health and Social Care Committee, *RoP [para 167]*, 15 November 2012

[56] National Assembly for Wales, Health and Social Care Committee, *RoP [para 117]*, 15 November 2012

out risk assessments and offering advice at an early stage could reduce the impact of diabetes or even prevent its development.

Recommendation 7: We recommend that future public health campaigns on diabetes should reflect the need to raise awareness of the risk factors associated with – and the early symptoms of - diabetes.

Role of community pharmacy

75. The Committee was told that community pharmacies could play a crucial role in spreading the message about the importance of having a risk assessment for diabetes. Dai Williams told us that Diabetes UK Cymru had held an initiative which pharmacies in Wales had signed up to, where risk assessments had been carried out by the pharmacies. Mr Williams told us that the initiatives had been successful, with 20,000 people having been assessed within 10 days. He believed that the easy accessibility of pharmacies had played an important role in drawing so many people to be assessed and that they should have an on-going role in carrying out the assessments and providing advice. He said:

> "They have a terrifically big role: you are walking down the road and you see a poster and it is easy to go into a pharmacy there and then and have a risk-assessment done… I would highly recommend providing an on-going risk assessment in pharmacies. It costs virtually nothing—we funded the last ones. That would make a huge difference. All pharmacists are trained and have been doing it for the last few years. That would be part of their routine. We should open the door to greater involvement with pharmacies so that they can provide lifestyle advice in the context of a broader public understanding of the dangers of diabetes and how to mitigate those dangers. That would be a way to move forward."[57]

76. Jason Harding went on to emphasise his belief that pharmacies should play a much bigger role in both diabetes prevention and care, especially as prevalence increases whilst NHS resources become more restricted. He said:

> "If you do not utilise pharmacies and just rely on primary and secondary care, with reducing resources and massive population groups with new waves of people coming through who potentially have these conditions, the system is not going to be able to cope. It

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[57] National Assembly for Wales, Health and Social Care Committee, *RoP [para 57-58]*, 15 November 2012

> is more a question of whether there are any other options to not include them."[58]

77. Representatives from Community Pharmacy Wales (CPW) told the Committee that pharmacists being able to carry out diabetes tests themselves rather than referring people to GPs would be beneficial to detecting incidences early on and would reduce pressure on GPs. Russell Goodway, Chief Executive of CPW, told the Committee that given the high number of people who could potentially be at high risk of developing diabetes, a pharmacist being able to conduct a test would lower the number being referred to their GP. He said:

> "…if pharmacies could go that one stage further and do the test, it would reduce the number of potential candidates being referred to the GP."[59]

78. Marc Donovan added that, whilst pharmacists were able to test blood-sugar levels, it would be beneficial if more pharmacies could carry out HbA1c tests[60], which were a more accurate indicator.[61] This would require local health boards to commission such tests as an enhanced service under the Community Pharmacy Contractual Framework.[62]

Medicine Use Reviews

79. The Committee also heard how pharmacists could play a proactive role in discussing the care of patients with diabetes during their annual medicine use review (MUR) meetings. MURs provide the opportunity for people to discuss their medication with their pharmacists, and the suggestion was put to the Committee that the meetings could be an additional means to supporting people with diabetes.

80. Paul Gimson, the Royal Pharmaceutical Society's Director for Wales, explained that diabetes was not currently one of the 4 areas pharmacists

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[58] National Assembly for Wales, Health and Social Care Committee, *RoP [para 67]*, 15 November 2012

[59] National Assembly for Wales, Health and Social Care Committee, *RoP [para 174]*, 15 November 2012

[60] A HbA1c test indicates a person's blood glucose levels for the previous two to three months

[61] National Assembly for Wales, Health and Social Care Committee, *RoP [para 177]*, 15 November 2012

[62] Community Pharmacy Contractual Framework, April 2005

were asked to target during MURs, and suggested that may be an area in which could provide better support to patients.[63]

81. Marc Donovan concurred that the MURs were an excellent opportunity to support patients, he said:

> "The MUR gives a real opportunity to sit down with a patient in a pharmacy to talk through their wider health needs, beyond their prescription, for example."[64]

Our view

82. The scale of the prevalence of diabetes in Wales means that all health professionals have an important role to play in ensuring people receive the best support to manage their condition and in raising awareness to reduce complications. Community pharmacies are in a prime position to participate in public health campaigns, carry out risk assessments and offer advice on lifestyle changes. We believe that community pharmacies should be included in any future campaigns to make the most of the services and support they can provide.

Recommendation 8: We recommend that the Welsh Government and health boards work together to expand the role of pharmacies in conducting risk assessments, to help improve early identification of people with diabetes. Pharmacies should also play a direct role in future public health campaigns. We believe the Welsh Government should specifically consider the value of including the HbA1c test for existing patients as an enhanced service as part of the Community Pharmacy Contractual Framework.

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[63] Half of all MURs conducted must be carried out with patients taking antihypertensive medication, medicines for respiratory disease, high risk medicines or identified as being as risk of wasting their medicines.

[64] National Assembly for Wales, Health and Social Care Committee, *RoP [para 185]*, 15 November 2012

6. Patient Education

83. Standard 3 of the National Service Framework relates to empowering people living with diabetes, and the NSF Delivery Strategy emphasises the importance of initial and on-going education and information. It states that:

> "The aim of such education and information is to facilitate and support self-management, and it needs to be available at the time of diagnosis and also later on."[65]

One of the actions set out in the NSF is the implementation of a structured education plan, based on a self-help programme for all people with diabetes, their families and carers.

84. The National Institute for Health and Clinical Excellence (NICE) recommends a structured programme of education for patients to help them to manage their condition, however a number of respondents to the Committee's consultation highlighted inadequate provision of structured diabetes education across Wales. Diabetes UK Cymru's evidence paper noted a failure to implement the NICE guidance on patient education for diabetes.[66] In his oral evidence, Jason Harding explained the benefits of a structured education programme both for improving an individual's health and the long term financial gains that fewer complications would bring to the NHS. He said:

> "people go into hospital when their diabetes is not managed properly and they experience complications. Structured diabetes education is put in place, hopefully as early as possible when somebody is diagnosed, to enable them to manage that more effectively."[67]

85. Mr Harding went on to refer to the results of a Diabetes UK survey conducted in 2008, to which 60% of the 8,000 respondents said that they did not understand the medication they were taking. Furthermore, the survey showed that 80% did not follow the self-management regime effectively.[68]

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[65] Welsh Government, National Service Framework for Diabetes in Wales: Delivery Strategy, March 2003 [accessed 9 November 2012]

[66] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

[67] National Assembly for Wales, Health and Social Care Committee, *RoP [para 33]*, 15 November 2012

[68] National Assembly for Wales, Health and Social Care Committee, *RoP [para 33]*, 15 November 2012

86. Witnesses agreed that patient education was at its most effective when delivered as soon as possible following diagnosis as people were generally more determined to make the changes to their lifestyle that would have a positive impact on their diabetes. There was concern among witnesses that not enough people were receiving the education they required at an early enough stage to make a difference. Dai Williams told the Committee:

> "We are continually meeting people in their late 20s who are suffering from the realisation that they have been managing it wrongly, because they have not had the psychological support earlier on, and they are facing the consequences in their 20s as opposed to their 30s and 40s. Of course, those people will be with the NHS with increasing difficulties, and increasingly expensive difficulties, that are affecting them for the rest of their lives."[69]

87. Lisa Turnbull, Policy and Public Affairs Adviser for the RCN, told the Committee that patients' experiences of the availability and benefits of education programmes varied depending on what was offered by their GP surgery. Ms Turnbull stressed the importance of a newly diagnosed person understanding the importance of participating in an education programme and the significant benefits it could bring to their condition. She explained that people should realise that an education programme was effectively similar to a prescription, in that it would bring them benefits as a drug would. Ms Turnbull also said that there was a responsibility on the person making the offer of education to understand the importance of participating in an education programme and to convey that message to the person to whom it is being offered.[70]

88. Julie Lewis, the Diabetes Specialist Nurse Lead for Wales, told the Committee that the timing of an education programme was key to its success:

> "When a person is newly diagnosed with diabetes, you have a window of opportunity in which they are quite motivated to make some changes, because it is a disastrous diagnosis. So, if that person then has to wait a long period of time until there is some intervention, six

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[69] National Assembly for Wales, Health and Social Care Committee, *RoP [para 37]*, 15 November 2012

[70] National Assembly for Wales, Health and Social Care Committee, *RoP [para 220]*, 29 November 2012

> months may have gone by and they do not feel any different, but the damage has been done."[71]

89. Ms Lewis went on to tell the Committee of a successful education programme in Deeside where, following diagnosis, a person's next appointment would be for a group education session about diet and lifestyle, and six months later they would then take part in a six-week programme for two and a half hours a week.[72]

90. Dr Chris Jones told the Committee that there was significant variation in the patient education offered by the different health boards, with some rates being alarmingly low. Additionally, information received by the Committee from health boards demonstrated the difference in provision, with no structured education programme being offered in some areas and waiting times being reported as lengthy in others where provision is available. Dr Jones acknowledged:

> "This clearly has been a disappointing area so many years after the publication of the NSF and of the reaffirmed NICE guidance in 2006. When we were monitoring the NSF, we were told that it was in place for type 1 and type 2 diabetes. Once we introduced the self-assessment, which was more quantitative, we learned that the organisations were reporting very low rates in some cases. There is clearly huge variation. For example, Abertawe Bro Morgannwg University Local Health Board reports that 50% to 75% of patients with diabetes get structured education; others report less than 5%. So, this area concerns us, because it is subject to a NICE technology appraisal. The NHS is supposed to take on board the recommendations from technology appraisals. They are highly evidence-based and will save money in the long term. That is one reason why the delivery group will have, as one of its outputs, the responsibility to ensure that that is now implemented properly."[73]

Our view

91. We recognise that being diagnosed with diabetes can be a devastating shock for some people. As a consequence, it is vital that support and

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[71] National Assembly for Wales, Health and Social Care Committee, *RoP [para 64],* 29 November 2012

[72] National Assembly for Wales, Health and Social Care Committee, *RoP [para 56-57],* 29 November 2012

[73] National Assembly for Wales, Health and Social Care Committee, *RoP [para 324],* 29 November 2012

guidance is available to help patients understand their condition and make changes to improve their lives. Equally, newly diagnosed people may not realise that diabetes is a serious condition that could have serious implications if left un-treated. We were very disappointed therefore to see such great variances in the level of structured education being offered across Wales and that waiting times for receiving education can be lengthy. The evidence we received was clear that education is most effective when provided at an early stage; appropriate education should therefore be offered at the time of diagnosis and made available shortly afterwards in order to help have a positive impact on peoples' lives.

92. The Committee believes that accessing structured education is as important as accessing medication and that there should be an expectation that people participate in an education programme as a matter of course within a short time of diagnosis. We were very pleased to hear about the success of the Deeside model, and believe that health boards must work together to share best practice and ensure consistent provision across Wales.

Recommendation 9: We recommend that the Welsh Government should urgently address the variances in the provision of structured education for people with diabetes. The forthcoming delivery plan should require all health boards to provide NICE-compliant structured education programmes and ensure equality of access to appropriate, timely education for all patients across Wales.

Insulin pump therapy

93. Insulin pump therapy is an alternative to injecting insulin. Insulin pumps work by delivering a varied dose of fast-acting insulin continually throughout the day and night, at a rate that is pre-set according to the patient's needs. It can be used by adults, teenagers, and children (with adult supervision) who have Type 1 diabetes, but it may not be suitable for everyone.

94. Dr Meurig Williams explained the long term benefits of using insulin pump therapy to manage diabetes, both for a person's wellbeing and the cost effectiveness for the NHS:

> "That [insulin pump] is a fantastic advance in the management of type 1 diabetes, but it is more expensive than giving insulin in the way that we have in the past. However, because it provides better control of the diabetes, the investment is worthwhile. It will be very cost-

> effective in the long run in reducing the number of advanced diabetic complications."[74]

95. Despite insulin pump therapy being a NICE approved technology and despite the benefits the therapy can bring to some people, concern was raised by witnesses that access to the therapy appeared to fall short of what was recommended by NICE. Dr Williams explained that whilst NICE recommended that between 10 – 12% of people with Type 1 diabetes should receive insulin pump treatment, the percentage of those who actually received it varied. Dr Aled Roberts told the Committee that the health board he represented, Cardiff and Vale, had not reached that target.[75] Additionally, Dai Williams told the Committee:

> "This is a NICE technology appraisal, which is mandatory, which means that there is a legal obligation to fulfil it and we are not doing it… It is not right for everyone, but the bottom line is that you are legally entitled to a pump if it is clinically appropriate. That is not happening in Wales, and I get many parents and many adults who are very upset about this."[76]

96. The Committee heard that the availability of education for people with Type 1 diabetes, which was a requirement of receiving insulin pump therapy, was a barrier to rolling the treatment out more widely. Dr Mike Page, Chair of the Welsh Endocrine and Diabetes Association, explained that people needed support in using insulin pumps, including understanding how food, exercise and illness can affect them. He said that patients needed training from professionals who were well trained themselves before being able to access the treatment, but if education teams were working to their capacities, they would be limited in terms of making it available to others. He said:

> "It is not just about giving a patient a pump. They have to be supported and they have to be taught how to use it… In order to support someone on to a pump, you need an educational team within the institution that is prescribing it that is itself trained and experienced in the use of pumps. These teams have a capacity. That

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[74] National Assembly for Wales, Health and Social Care Committee, *RoP [para 129],* 15 November 2012

[75] National Assembly for Wales, Health and Social Care Committee, *RoP [para 140-141]*, 15 November 2012

[76] National Assembly for Wales, Health and Social Care Committee, *RoP [para 53-54],* 15 November 2012

> capacity can be reached and, at that point, you cannot start anyone else on a pump."[77]

97. There was agreement among witnesses that while insulin pump therapy was not an appropriate treatment for everyone, it could make a real difference to those for whom it was suitable. There was also collective agreement that the improvements it could bring to managing diabetes could lead to fewer long term complications, which would lead to less treatment being needed later on. This, it was argued, could make insulin pump therapy cost effective, despite the initial higher costs associated with it. Dr Phil Evans summed up the benefits of the therapy:

> "It is a NICE technology appraisal, so it has looked at the cost-effectiveness in the right and appropriate patient. In that patient, that would be an excellent therapy and it should be available to them."[78]

Ring-fenced funding

98. In its written evidence to the Committee, Diabetes UK Cymru said that the Welsh Government's new draft diabetes delivery plan included a re-commitment to insulin pump therapy, and suggested that a ring fenced budget was required specifically to fund it. Their evidence referred to the situation in Scotland and Northern Ireland, where budgets of £1.5 million and £2.5 million respectively were ring fenced for the provision of the treatment.[79]

99. Despite the costs of the insulin pumps, witnesses from the Diabetes and Endocrinology National Specialist Advisory Group believed that providing the support and training required to accompany the therapy was more of a barrier to providing the treatment. Dr Phil Evans and Dr Mike Page said that, in their experiences, cost had not prevented the prescription of a pump, but rather the availability of Type 1 structured diabetes education and the people to provide that education had been the main barrier.[80]

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[77] National Assembly for Wales, Health and Social Care Committee, *RoP [para 70],* 29 November 2012

[78] National Assembly for Wales, Health and Social Care Committee, *RoP [para 75],* 29 November 2012

[79] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

[80] National Assembly for Wales, Health and Social Care Committee, *RoP [para 77-79],* 29 November 2012

Our view

100. The Committee accepts the evidence that insulin pump therapy is not a suitable treatment for everyone, however for those it can help, the improvements can be life changing. We recognise the importance of the NICE appraisal and the weight this adds to the value of the treatment. We welcome the Welsh Government's commitment to the therapy in its draft diabetes delivery plan, but believe there should also be a commitment to providing the resources required to accompany the treatment, especially the structured education and training on how to use the pumps. We note the potential long-term savings that can be made by health boards through the use of the pump therapy, and the improvements it can make to a person's quality of life.

Recommendation 10: We believe that insulin pump therapy and the necessary accompanying education should be available to all suitable candidates to improve their quality of life. We recommend that the Welsh Government's forthcoming delivery plan include a requirement to improve the availability of education and training on the use of insulin pumps.

7. Secondary care

101. The Committee was told that, at any given time, between 15-20% of hospital in-patients were diabetic. Furthermore we were told that, when admitted to hospital, people with diabetes generally have a greater length of stay and experience more complications.[81]

102. Dr Leo Pinto, Consultant Physician and Clinical Director at Aneurin Bevan Health Board told the Committee that the National Diabetes in-patient audit had confirmed the high proportion of diabetics among hospital patients, he said:

> "The audit highlighted that one in five people in hospital have diabetes. People with diabetes are over-represented in hospitals, compared with the community, where one in 20 people have diabetes. In hospital, there is a much higher proportion because people with diabetes are more likely to need hospital admission. Most often, it is due to an acute medical illness, or it may be due to the need for elective surgery. So, in other words, there are lots of people with diabetes in hospital."[82]

103. Concerns were raised with the Committee regarding the treatment of insulin dependent diabetics in hospitals as variations in diet could lead to changes in their blood-glucose levels. Dr Leo Pinto said:

> "It is people on insulin treatment who are at particular risk because, when they are acutely ill and go into hospital, many things change. For example, their food intake will change; they may not feel like eating…Many people with diabetes are at risk of hypoglycaemia."[83]

Public Services Ombudsman Wales recommendations

104. The Public Services Ombudsman for Wales conducted an inquiry into the care of a diabetic patient, Mr David Joseph, following his admission to Bronglais Hospital in December 2008. In written evidence to the Committee, Mr Joseph's daughter, Amelia Bertram, said that while at Bronglais Hospital, her father became hypoglycaemic, aspirated his vomit and suffered a

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[81] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB11 – Diabetes UK Cymru*

[82] National Assembly for Wales, Health and Social Care Committee, *RoP [para 19]*, 21 November 2012

[83] National Assembly for Wales, Health and Social Care Committee, *RoP [para 18]*, 21 November 2012

respiratory and cardiac arrest. She said that he subsequently required 24 hour nursing care, and following his discharge to a nursing home during April 2009, he died a few days later.[84]

105. In his report, the Ombudsman found that failure to monitor Mr Joseph's blood glucose levels after admission to hospital had led to the hypoglycaemia attack, and made recommendations to Hywel Dda Health Board to avoid similar occurrences.[85]

106. The Ombudsman recommended that the health board review the skills and knowledge of all nursing staff on medical wards regarding blood sugar monitoring and diabetic care and take appropriate action. He also recommended that the health board provide training to all nurses in medical wards on the significance of oxygen blood levels.[86] Given the nature of the case, there were clearly implications for all health boards in Wales arising from the Ombudsman's recommendations and lessons to be learnt.

107. The Committee heard that following the Ombudsman's report, David Sissling, Chief Executive of NHS Wales, had written to all health boards to inform them of the recommendations. He told the Committee that Health Inspectorate Wales would monitor the progress made by the health boards in implementing the recommendations.[87]

ThinkGlucose Campaign

108. The 'ThinkGlucose' package developed by the NHS Institute for Innovation and Improvement includes a toolkit to support improvement to care for diabetic patients.[88] The Committee learnt that the package had been rolled out across Cwm Taf Health Board, with nurses and junior doctors being trained to use 'hypo-boxes', which were available on all wards. Dr Leo Pinto told the Committee, however, that Aneurin Bevan Health Board had been unable to adopt the ThinkGlucose programme in its entirety due to financial constraints, but had taken on board aspects of it:

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[84] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 18 – Amelia Bertram*

[85] Public Services Ombudsman for Wales, *The investigation of a complaint by Ms R against Hywel Dda Local Health Board: A report by the Public Services Ombudsman for Wales: Case 201100456*, April 2012

[86] Public Services Ombudsman for Wales, *The investigation of a complaint by Ms R against Hywel Dda Local Health Board: A report by the Public Services Ombudsman for Wales: Case 201100456*, April 2012

[87] National Assembly for Wales, Health and Social Care Committee, *RoP [para 300]*, 29 November 2012

[88] http://www.institute.nhs.uk/option,com_joomcart/Itemid,194/main_page,document_product_info/cPath,86/products_id,611/Joomcartid,quqvchhulcrddqaf1ski60o1q2.html

> "ThinkGlucose is a national campaign. We have not been able to adopt the ThinkGlucose campaign in our health board because of the financial constraints, but we have adopted the good aspects of the ThinkGlucose campaign. For example, we have introduced HypoBoxes on wards—boxes that contain the necessary material to treat hypoglycaemia. They were introduced in the health board over a year ago, and they are on every ward. The staff have been provided with the necessary training to identify people with low blood glucose."[89]

109. Dr Pinto went on to tell the Committee that the adoption of certain aspects of the ThinkGlucose programme, such as the hypo boxes, had improved patient safety, but he believed that implementing the whole package would improve care even further. He told the Committee that the cost of implementing the ThinkGlucose package was £18,000 per hospital site, and that the financial restraints were a barrier to full adoption:

> "The cost of acquiring the ThinkGlucose package is around £18,000 a year. When we presented our case to the executives, the health board's financial position was quite difficult and our remit was to improve quality of care within the existing resources, so that is what we have been trying to do. However, on whether the ThinkGlucose package would help to improve the care further, the answer is 'yes, it certainly would'. The improvements made would be spread across the health board and maintain that level of standard. So, adopting a ThinkGlucose programme across all health boards in Wales would be a positive step in the right direction."[90]

110. Nicola Davis-Job, Acute Care Adviser for RCN Wales, suggested to the Committee that the ThinkGlucose programme would be a good campaign to be promoted by the 1000 Lives Plus scheme to promote awareness of the importance of monitoring blood glucose levels and using the hypo boxes. She told the Committee that:

> "…it would be excellent if the 1000 Lives Plus people were to embrace that [ThinkGlucose campaign] and we could have general

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[89] National Assembly for Wales, Health and Social Care Committee, *RoP [para 20]*, 21 November 2012

[90] National Assembly for Wales, Health and Social Care Committee, *RoP [para 25]*, 21 November 2012

> nurses using that campaign in the same way that they have used the hand washing or the sepsis campaigns, which have gone really well."[91]

111. Dr Chris Jones, Medical Director for Wales, told the Committee that it was a decision for health boards should they wish to implement the ThinkGlucose initiative, however the Welsh Government would be supportive of any who decided to do so.[92]

Our view

112. As such a high proportion of hospital patients have diabetes, it is vital that their package of care meets the needs of their diabetes in addition to any other treatment they receive. People with diabetes should be safe whilst in hospital and should be confident that the care they receive is appropriate for their diabetes. It is essential that medical staff are able to identify diabetes-related problems in patients and are able to provide appropriate treatment.

113. The case of David Joseph highlighted the dangers of a person's blood sugar level falling too low, and the importance of medical staff being able to recognise these signs. The Committee welcomes the introduction of the ThinkGlucose programme as an easily accessible method of administrating treatment for patients who experience low blood sugar. We believe that rolling out the project to other health boards would improve patient care.

Recommendation 11: We recommend that the ThinkGlucose programme should be introduced in all health boards across Wales.

Role of diabetes specialist nurses

114. Witnesses told the Committee that diabetes specialist nurses played a very important role in improving the care of diabetes patients, however concern was expressed that the number of specialist nurses had fallen over recent years, and that those who remained had seen the balance of their work change by taking on more general duties.

115. RCN Wales raised concern in their written evidence that some diabetes specialist nurses were increasingly being asked to return to work on general

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[91] National Assembly for Wales, Health and Social Care Committee, *RoP [para 215]*, 29 November 2012

[92] National Assembly for Wales, Health and Social Care Committee, *RoP [para 298]*, 29 November 2012

hospital wards, thereby reducing the time available to concentrate on supporting diabetic patients. Their evidence said:

> "RCN Wales is concerned that some Health Boards in Wales are asking Diabetes Specialist Nurses and Paediatric Diabetes Specialist Nurses to return to work on general hospital wards for an increasing part of their working week. This is part of a general move to try to backfill the sickness and maternity cover of ward staff and avoid replacing the posts of the ward staff who leave. Role modelling and teaching is part of the role of the specialist nurse but this policy is leading to patient case load being less well managed, nurse lead clinics being cancelled and people with diabetes not being supported fully."[93]

116. Julie Lewis, the Diabetes Specialist Nurse Lead for Wales, concurred with the RCN view that the number of diabetes specialist nurses had decreased and that those who remained were required to spend part of their time working on general wards. She said that this trend had had an impact on their ability to maintain the service they provided:

> "We have posts that have been frozen and maternity leave that is not covered. When you have a very small team of specialists, that has a huge impact on your ability to maintain a service."[94]

117. There was agreement among witnesses that it would be helpful to have a guideline figure for the number of diabetes specialist nurses required per head of population to meet the services needed. Julie Lewis told the Committee that such a guideline would allow health boards to measure their ability to provide a diabetes service and would assist in identifying gaps in provision across Wales. She said:

> "…we do not have a recognised number of diabetes nurses per prevalence or per population, and there are models out there. So, there is huge variability across Wales… So, if there were a recommended number of diabetes specialist nurses per population—and dieticians, as well, I have to say—health boards would at least

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[93] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 10 – RCN Wales*

[94] National Assembly for Wales, Health and Social Care Committee, *RoP [para 87]*, 29 November 2012

> have some idea of a baseline against which to measure their diabetes nursing service."[95]

118. Nicola Davis-Job suggested to the Committee that a guideline figure for the number of specialist nurses per population would be preferable to a per-bed figure, given that the nurses work across both primary and secondary care. The figure she suggested as a guideline was one nurse per 50,000 of the population.[96]

Information Technology systems

119. Dr Mike Page, Chair of the Welsh Endocrine and Diabetes Association, told the Committee that it could sometimes take a couple of days for diabetic patients to become known to the diabetes specialist staff, which therefore delayed how quickly the staff could get involved in the patients' care.[97] Being made aware of diabetic patients at an early stage would be beneficial to ensure that their care addressed their diabetes in addition to any other condition they may have been admitted for treatment.

120. The written evidence from Diabetes UK Cymru also referred to diabetic services having been hampered by the lack of an effective secondary care IT system. It went on to say that the Diabetes Delivery Plan consultation published by the Welsh Government, committed NHS Wales to establishing a new "integrated diabetes patient management system," which it hoped would improve the situation. Dr Page believed that, if introduced, the proposed new IT system would help in identifying patients when they arrive in hospital and target specialist diabetes care. He said:

> "The IT solution that is being proposed—which we are encouraged to believe might be introduced—will help that. There are two factors here: one is knowing who the patients are the minute they arrive, and the second is being able to target the limited resources to go to see them."[98]

121. The integration of diabetes services and the role played by ICT in this is explored in chapter 4.

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[95] National Assembly for Wales, Health and Social Care Committee, *RoP [para 92]*, 29 November 2012

[96] National Assembly for Wales, Health and Social Care Committee, *RoP [para 189]*, 29 November 2012

[97] National Assembly for Wales, Health and Social Care Committee, *RoP [para 18]*, 29 November 2012

[98] National Assembly for Wales, Health and Social Care Committee, *RoP [para 18]*, 29 November 2012

Our view

122. Diabetes specialist nurses play a key role in supporting diabetic patients to ensure they receive the treatment and information they require. The Committee was concerned to learn of the fall in the number of diabetes specialist nurses, especially as the number of people with diabetes continues to rise.

123. We welcome the proposal for a new patient management system; we hope that this will be introduced and that it can address the issue of identifying diabetic patients on admission to hospital so that they can receive targeted care from the outset.

Recommendation 12: We recommend that the Welsh Government undertake an audit of the number of diabetes specialist nurses in post across Wales, and the proportion of their time spent on general duties. The Welsh Government should consider the merits of issuing guidance to health boards on recommended numbers of diabetes nurses per head of population.

8. Retinal screening

124. Diabetic retinopathy is a common complication of diabetes, caused by high blood sugar levels damaging the network of tiny blood vessels that supply blood to the retina. If not treated, it can lead to blindness. The evidence paper from the Diabetic Retinopathy Screening Service for Wales (DRSSW) described diabetic retinopathy as the most common cause of blindness amongst working age adults in the UK.

125. The DRSSW is an all-Wales service designed to detect sight-threatening diabetic retinopathy at an early stage, ensuring early treatment and preventing loss of vision. The service is a key element of the NSF Delivery Strategy.

126. Many people will be asymptomatic until the disease is very advanced. In their written evidence, the DRSSW stated that the risk of visual impairment and blindness was substantially reduced by a care programme combining methods for early detection with effective treatment of diabetic retinopathy. The Committee was told that:

> "The key issue in screening for diabetic retinopathy is to identify those people with sight-threatening retinopathy who may require preventative treatment. Early detection of sight threatening retinopathy and treatment with laser therapy can help prevent sight loss. Currently all eligible people with diabetes aged 12 and over are offered routine, annual screening invitations, based on UK NSC guidance."[99]

127. Richard Roberts, representing the DRSSW, told the Committee that the target was to refer everyone diagnosed with diabetes for screening, to see whether there was any evidence of diabetic retinopathy. He said that the uptake of appointments was approximately 82-84%, with attendance varying by region.[100]

128. The DRSSW was designed as a community-based service, operating from mobile units which visit sites in each health board area. Its written evidence noted that diabetes has a predilection for the vulnerable and disadvantaged

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[99] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 4 – Diabetic Retinopathy Screening Service for Wales*

[100] National Assembly for Wales, Health and Social Care Committee, *RoP [para 129 & 131]*, 29 November 2012

sections of society, and stated that the clinic sites are chosen to allow all patients reasonable and equitable access.

129. The Committee heard evidence that the DRSSW was a success story and that the screening had had a huge impact on lowering eye conditions associated with diabetes. Mr Roberts told us that the figures for Wales compared very favourably to other areas, with Wales faring 18% better than elsewhere in the UK. He added that he would expect a diabetic person to retain normal vision for the rest of their life, which would not have been possible years ago, a turnaround which the screening service had made a huge contribution to achieving.[101]

130. Dr David Minton, representing Aneurin Bevan Health Board, described the DRSSW as an outstanding service, but noted a concern that it may be overrun with too many patients and as a result the annual checks may be slipping to every 15 or 18 months.[102] Written evidence from BMA Cymru also stated the all-Wales service worked well, but that it was stretched and there were reports of the annual review slipping to every 15 months.[103]

131. Another concern raised with the Committee was that there was still a proportion of people with diabetes who did not participate in the screening programme. Richard Roberts cited elderly people as one group for whom it was often difficult to reach, especially if they were unable to get to appointments. He also told us that further work was needed to engage with diabetic people at an early stage to reach people who may not realise the importance of participating in the programme.[104]

Our view

132. The Committee applauds the success of the Diabetic Retinopathy Screening Service for Wales. We acknowledge, however, that we should not be complacent about its success and that work should continue to improve participation levels further. A proportion of people who have not engaged with the service remain; as such, it remains vital that efforts continue to target those who have not yet benefited from the screening programme. We recognise the importance of diabetic people understanding the impact their

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[101] National Assembly for Wales, Health and Social Care Committee, *RoP [para 156 & 158]*, 29 November 2012

[102] National Assembly for Wales, Health and Social Care Committee, *RoP [para 69]*, 21 November 2012

[103] National Assembly for Wales, Health and Social Care Committee, *Consultation Response DB 16 – BMA Cymru*

[104] National Assembly for Wales, Health and Social Care Committee, *RoP [para 161]*, 29 November 2012

condition can have on their eyesight, and believe that national education programmes should convey this message to everyone. The Diabetic Retinopathy Screening Service for Wales should be recognised as a success story and a model from which other services can learn.

Recommendation 13: We recommend that the Welsh Government monitors the capacity of the Diabetic Retinopathy Screening Service to provide annual checks for diabetic patients as the growing prevalence of diabetes increases demand for the service.

Annex A – Witnesses

The following witnesses provided oral evidence to the Committee on 15, 21 and 29 November 2012. Transcripts of the oral evidence sessions can be viewed, in full, at:
http://www.senedd.assemblywales.org/mgIssueHistoryHome.aspx?IId=1309

15 NOVEMBER 2012	
Session 1	
Dai Williams	Diabetes UK Cymru
Jason Harding	Diabetes UK Cymru
Session 2	
Dr Meurig Williams	Royal College of Physicians
Dr Aled Roberts	Association of British Diabetologists
Dr Ian Millington	BMA Cymru
Dr Mark Temple	BMA Cymru
Session 3	
Mair Davies	Royal Pharmaceutical Society
Paul Gimson	Royal Pharmaceutical Society
Russell Goodway	Community Pharmacy Wales
Marc Donovan	Community Pharmacy Wales
21 NOVEMBER 2012	
Session 4	
Dr Sharon Hopkins	Cardiff and Vale University Health Board

Dr Leo Pinto	Aneurin Bevan Health Board
Dr David Minton	Aneurin Bevan Health Board
Session 5	
Dr Hugo van Woerden	Public Health Wales
29 NOVEMBER 2012	
Session 6	
Dr Phil Evans	Diabetes and Endocrinology National Specialist Advisory Group
Dr Mike Page, Chair	Welsh Endocrine and Diabetes Society
Julie Lewis	Diabetes specialist nurse lead for Wales
Dr David Millar-Jones	Diabetes Research Network Wales
Session 7	
Dr Richard Roberts	Diabetic Retinopathy Screening Service for Wales
Session 8	
Lisa Turnbull	RCN Wales
Nicola Davies-Job	RCN Wales
Session 9	
David Sissling	Welsh Government
Dr Chris Jones	Welsh Government

Annex B – Written evidence

The following people and organisations provided written evidence to the Committee. All written evidence can be viewed in full at http://www.senedd.assemblywales.org/mgIssueHistoryHome.aspx?IId=4164

Organisation	*Reference*
Neath Port Talbot Council for Voluntary Service	DB 1
Juvenile Diabetes Research Foundation	DB 2
Abertawe Bro Morgannwg University Health Board	DB 3
Diabetic Retinopathy Screening Service for Wales	DB 4
Diabetes and Endocrinology National Specialist Advisory Group	DB 5
1000 Lives Plus / Public Health Wales	DB 6
Alliance Boots	DB 7
Association of British Clinical Diabetologists and Royal College of Physicians	DB 8
ABPI Wales	DB 9
RCN Wales	DB 10
Diabetes UK Cymru	DB 11
Robin V Wright	DB 12
Patients Association	DB 13
Tegryn Jones	DB 14
Hywel Dda Health Board	DB 15
BMA Cymru	DB 16
Aneurin Bevan Health Board	DB 17
Amelia Bertram	DB 18
Cardiff and Vale University Health Board	DB 19
Betsi Cadwaladr University Health Board	DB 20
Cwm Tâf Health Board	DB 21

National Pharmacy Association	DB 22
Royal Pharmaceutical Society	DB 23
British Dietetic Association Welsh Board & Welsh Dietetic Leaders Advisory Group	DB 24
Community Pharmacy Wales	DB 25