

Scrutiny Review of Health Inequalities: Diabetes

Report of the Adult Services and Health Scrutiny Panel

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1 EXECUTIVE SUMMARY

As part of its 2010/11 work programme, Adult Services and Health scrutiny panel set up a review group to examine patient experience of care and support in relation to the diagnosis and management of diabetes in Rotherham. This report sets out the process and findings, and makes recommendations for improving services.

The review methodology was based on a pilot model developed by Doncaster Council's Health Overview and Scrutiny Committee, which provides a structured approach to reviewing health inequalities. The review took place between August and October 2010

Summary of Key Findings

- There are 11,650 adults (aged 17 or over) diagnosed with diabetes in Rotherham based on 2009/2010 data¹
- And an estimated 4,150¹ adults with undiagnosed diabetes, which highlights the need for awareness raising and education in relation to early symptoms in high risk groups
- NHS Rotherham have undertaken a project to redesign diabetes services in the borough, addressing a number of issues relating to patient diagnosis and care
- Obesity and unhealthy lifestyles are prevalent in Rotherham, along with high levels of deprivation; raising awareness of the risk factors and focusing on prevention is needed to reduce the rise in diabetes
- There is a lack of awareness of the condition with some health professionals, which has raised questions in relation to the management of the condition when patients with diabetes attend hospital for another unrelated issue
- There is good support for patient groups such as Diabetes UK within the hospital, but there may be ways of promoting their services wider and utilising the knowledge and experience of groups such as this
- There is poor take-up of structured education for newly diagnosed patients, which may be a result of lack of awareness and understanding of the benefits to attending the programme

¹ Rotherham PCT Diabetes Community Health Profile (2010). Yorkshire & Humber Public Health Observatory

Summary of Recommendations

The recommendations have been made under four specific themes, from prevention and education to early diagnosis, good practice and better self-management:

- The new statutory Health and Wellbeing Board will provide a way of coordinating all partners to focus on prevention of unhealthy lifestyles, which will subsequently reduce diabetes and inequalities across the borough
- Prevention of obesity and raising awareness of the risk factors in both children and adults needs to be the main focus in reducing the prevalence of diabetes
- Need to maximise take-up of NHS Health Checks and widely promote the range of information sources available to inform people about risk factors and early symptoms
- Focus on education and early diagnosis of symptoms (potentially through the NHSR diabetes testing equipment) needs to be targeting at high risk groups
- The work being undertaken to redesign diabetes services in Rotherham needs to be supported and providers responsible for implementing this need to be held to account by the Health and Wellbeing Board to ensure continued improvement in outcomes for patients
- Structured education for newly diagnosed patients is a key tool for supporting people to manage their condition, ways of encouraging this need to be considered
- Better links need to be made with patient groups such as Diabetes UK, as well as LINKs and HealthWatch once established to understand patient experience

2 METHODOLOGY FOR REVIEWING HEALTH INEQUALITIES

A model for reviewing health inequalities has been piloted by Doncaster Council's Health Overview and Scrutiny Committee to provide a structured approach to reviewing inequalities relating to a particular medical condition, a service being delivered to patients, or issues within a specific neighbourhood. It has been designed to provide members of the scrutiny panel with an opportunity to research issues within their own constituencies, require commissioners and service providers to provide information, pose questions to identify gaps and then reach conclusions about the need for change.

The decision was taken to utilise elements of the Doncaster model for the purpose of the Rotherham review to help in understanding the broad range of issues in relation to diabetes, including; general awareness of the associated risk factors and possible issues faced by patients during diagnosis and management of their condition.

The model is based around a number of components which took place between August and October 2010:

- Initial notification of review subject and the requirement of expert opinion
- Questionnaires to all review Members to consider issues within their constituencies
- Desk top research to look at existing practice and policy framework
- Group discussions with clinical expertise

3 KEY FINDINGS

3.1 Redesign of Rotherham Diabetes Services

NHS Rotherham has undertaken a piece of work to help in understanding issues in relation to diabetes services locally. Through discussions with various providers in Rotherham, the following issues were identified:

- There was no intermediate level of care between care provided by the GP and specialist care provided by the hospital
- There had been variation in outcomes and prescribing costs per person with particular concern about insulin prescribing
- There was a shortage of structured education for people with diabetes and in particular top-up education for people with type II diabetes
- There was fragmentation of the specialist diabetes team
- There was a lack of incentive for GPs to take on more advanced management of diabetes in primary care such as insulin initiation and review

The redesign of the diabetes pathway started in March 2010 and is due for completion April 2011. The purpose of the redesign is to improve the effectiveness of diabetes care as measured by practices achieving higher levels of good outcomes for patients. The new model includes 3 levels of care, from essential primary care, to enhanced primary care services and secondary care. Following completion the responsibility to implement this new model will be with the providers; GPs and Rotherham Foundation Trust and this review makes recommendations to support this new model and ensure it is implemented and monitored to continually improve outcomes for Rotherham patients.

3.2 In-patient Services

The review found anecdotal evidence of poor management of diabetes when patients were attending hospital as an in-patient for another matter.

There was evidence of problems in getting ward staff in hospitals released for training purposes, which may be a reason for the poor management of diabetes with in-patients, due to lack of awareness and appropriate skills to

manage the condition. Getting access to the diabetic specialist nurse also appeared to be an issue in some cases.

3.3 Patient Groups

There is good support for the Rotherham branch of Diabetes UK at Rotherham Hospital. Diabetes UK produce a range of leaflets and posters about the charity and services they offer, which are distributed around the hospital. There may also be potential to promote Diabetes UK and their services much wider and utilise their knowledge and experience in helping to design appropriate services in the future.

Other groups such as LINKs and Local HealthWatch, once established, may also provide essential knowledge in relation to service redesign and providers and commissioners of services (NHSR at present, then GP commissioning consortium once established) also need to ensure they are linked up to these user groups.

3.4 Retinopathy Screening

A number of issues were raised in relation to the diabetic eye screening service. Issues raised included:

- No location map of Maltby Service Centre sent with appointment letter and inadequate signage for patients attending retinopathy tests there
- Choice of location (between Rotherham Hospital and Maltby Service Centre) was not always communicated to patients, but this is being looked into following a complaint made by one of the patients
- Choice of location is particularly important given many patients' need for public transport as they are unable to drive after the test.
- When testing is done at Maltby, feedback is not available on the day; instead, the results are posted to the patient up to 6 weeks later.
- A further source of confusion is the fact that the tests are administered by Barnsley Hospital NHS Foundation Trust and the correspondence reflects this, even for patients from Rotherham.
- Service is only open 4.5 days per week

Following investigation into these issues, they had been picked up and dealt with directly by the Barnsley and Rotherham Diabetic Eye Screening Service and assurance has been made to the patients (through Diabetes UK) that they will continue to develop the service to ensure a positive patient experience.

3.5 GP Services

Diagnosis and subsequent care through GPs appears to be good, but there may be scope for more follow-up, such as GP-based diabetic groups where newly diagnosed patients can get reassurance.

GPs currently refer newly diagnosed patients to a structured education programme (see DAFNE and DESMOND below), however, although there is evidence that this service helps patients with management of their condition and therefore potentially reduces their need for time off work due to sickness and more serious complications in the future, there are a number of perceived barriers to patients accessing this service. Patients may feel they are unable to take time off work to attend the programme and may also be reluctant to inform their employer, there may also be feelings of anxiety which prevents them from attending. Ways of encouraging patients to attend this service and ensuring they receive the appropriate information in relation to the benefits of attending need to be considered.

3.6 Management, Treatment and Training

DAFNE (Dose Adjustment for Normal Eating) is a five day course for people with type I diabetes. DAFNE is a way of managing Type 1 diabetes and provides people with the skills necessary to estimate the carbohydrate in each meal and to inject the right dose of insulin.

DESMOND is aimed at newly diagnosed type II patients. It provides 6 hours of nurse lead group education via a formal curriculum. Each group consist of 6-10 people newly diagnosed with Type II diabetes and each person a can choose to be accompanied by a partner, family member or friend.

Lifestyle changes, early detection and good management all result in better outcomes for people with diabetes, however, self-denial (or lack of understanding) when early symptoms develop appear to be an issue with some individuals, suggesting a clear need for patients and service providers to be appropriately trained and educated in diabetes, to understand the potential issues and ways to appropriately manage condition.

There are also a number of resources available for health professionals to support them when working with people with learning disabilities, who are a significantly higher risk group due to a lack of awareness of the risk factors and symptoms and potentially poorer access to services and understanding of their needs by health professionals. "My Health" is a training initiative developed by Speakup Self Advocacy, the training focuses on diagnostic overshadowing, the health inequalities faced by people with learning disabilities and reasonable adjustments to practice. To date over 300 health professionals including GPs, Nurses, Receptionists and Practice Managers have attended these training sessions within Rotherham. "I'm a Person Too!" is a national training initiative aimed at improving the communication techniques of public and private sector organisations when working with people with learning disabilities and "Bywater" is an online resource based on the Knowledge and Skills Framework aimed at improving the service offered to people with learning disabilities within hospitals. The resource uses online video clips, knowledge tabs and assessments to improve participants' knowledge, presently there are 4 levels and this is being trialled within Rotherham Foundation Trust from January 2011.

4 RECOMMENDATIONS

Responsibility for Public Health will be moving over to local authorities when PCTs cease to exist in 2013, which increases the potential for a more joined-up public health message with regard to healthy lifestyles through the Health and Wellbeing Board.

The recommendations look at ways of improving care and services now as well as through the transition to this Board being established, set out under four specific themes.

Education and Prevention

- 4.1 Ensure the remit of the Health and Wellbeing Board focuses on the **promotion** of healthy lifestyles such as good diet, physical activity and the prevention of obesity, through the development of the partnership Health and Wellbeing Strategy
- 4.2 NHS Rotherham to ensure links are made with the community weight management services such as Reshape and the Carnegie Clubs to ensure those at risk of diabetes due to being overweight or obese are made aware of the risks and sign-posted to early support where this may be appropriate
- 4.3 RMBC to investigate the possibility of putting diabetes awareness on PSHE curriculum.
- 4.4 Ensure GPs continue to raise awareness and inform patients of the risk factors and early symptoms, through the GP consortium and Health and Wellbeing Board once established

Early Diagnosis

- 4.5 Investigate ways of encouraging people to seek advice through the range of sources available, such as GP practices, pharmacies and NHS Direct, through the council and NHSR websites and the use of posters/leaflets available through Diabetes UK
- 4.6 Consider ways of utilising the EzScan machine owned by NHSR as widely as practicable with high risk groups and communities, such as BME and older people – and investigate the possibility of training other staff (RMBC/NHSR) and volunteers to use the machine due to a lack of staff resource currently available to do this.
- 4.7 NHSR and the Health and Wellbeing Board (once established) to investigate ways of maximising the take-up of the NHS Health Checks Programme which can help to identify those with diabetes as well as other long term cardiovascular diseases earlier.

Spreading Good Practice

- 4.8 Support recommendations included in the redesign of diabetes services which was undertaken by NHSR and ensure that this is implemented by holding the GP consortium and relevant providers to account through the Health and Wellbeing Board once established

Ensure the Health and Wellbeing Board looks at performance in relation to service and patient improvements, resulting from the redesign of services, and refers relevant issues to Health Scrutiny where they feel it is necessary

- 4.9 NHSR to work with GPs and the Specialist Diabetes Service to look at ways of encouraging newly diagnosed patients to complete structured education and ensuring GPs are promoting this to patients and reassuring those who may perceive barriers to attending (such as lack of time and feelings of anxiety)

Better Self-management

- 4.10 Ensure NHSR are engaged with the Rotherham branch of Diabetes UK and other patient groups, such as LINKs (and HealthWatch once established) to raise awareness as well as understand patient experience of their condition and the services provided for them in order to inform improvement in the quality of services.

5 BACKGROUND

Diabetes is a long-term condition with far reaching implications for people living with it and their families and carers. These range from the need to adopt a suitable diet, to possible long-term complications such as aggravated heart disease and diabetes is the leading cause of blindness and renal failure and (after accidents) the biggest cause of lower limb amputation. The average life-expectancy of people living with the condition is also considerably reduced if not managed properly.

There are two types of diabetes:

- Type I is genetic and begins in childhood
- Type II begins in adulthood and is influenced by lifestyle/diet and ethnicity

Diabetes does not impact upon everyone in society equally. Significant inequalities exist in the risk of developing diabetes, in access to health services and the quality of those services, and in health outcomes, particularly with regard to people with Type II diabetes. Those who are overweight, physically inactive or have a family history of diabetes are at increased risk of developing diabetes. People of South Asian, African, and African-Caribbean descent have a higher than average risk of developing Type II diabetes, as do less affluent individuals and populations. Socially excluded people, including prisoners, refugees and asylum seekers, and people with learning difficulties or mental health problems may receive poorer quality care. The knowledge that people have about their diabetes also varies considerably.

5.2 Prevalence

Prevalence of diabetes is increasing and has more than doubled in the last 10 years. Nationally, over 5% of men and over 4% of women have diagnosed diabetes.

In Rotherham there are 39 GP practices, caring for over 11,000 people with diabetes of which 2500 are on insulin.² There are 10 people diagnosed with type II diabetes for every person diagnosed with type I. But prevalence of both types is increasing. However, the actual prevalence of diabetes locally may be less than predicted and suggests there may be approximately 4000 people with undiagnosed diabetes across the district.

Diabetes prevalence is forecast to grow at 2.5% per year, which could mean 16,500 diabetics in Rotherham by 2020.³ The longer someone has diabetes, the greater chance of complications such as blindness and circulatory problems.

5.3 Risk Factors

People from deprived areas are considerably more likely than those from more affluent areas to die from diabetes complications. In Rotherham, there are relatively high levels of deprivation across the borough which may be related to the higher numbers of people with type II diabetes.

Rotherham also has a high prevalence of overweight and obesity in adults and children. Most GP practices have over 50% of patients with a BMI of 25+ which is a major concern in relation to the growing number of people diagnosed with diabetes

The links between type II diabetes and obesity are firmly established. Without the intervention of a healthy diet and appropriate exercise, obesity may develop into diabetes over a relatively short period of time. There is clearly a need for any interventions to reduce diabetes in the Borough to focus on prevention and support people to take-up and maintain healthy lifestyles.

5.4 Current Spend

Spend in 2008-09 was around £2.3 million per 100,000 total population which is about average for similar PCTs. However, there is considerable variation between practices within Rotherham in relation to risk factor management and outcomes, suggesting there is potential for sharing good practice across the borough.

² QUEST Qtr 2 2009

³ NHS Rotherham Redesign of Diabetes Services 2010

NHS Rotherham has the highest level of insulin prescribing within Yorkshire and the Humber and there is considerable variation in its use within the district. Some of this may be due to prevalence of diabetes within different practices and experience of managing diabetes, however there is also a variation in the types of insulin used which impacts on costs; there are plenty of practices achieving higher levels of good outcome using low cost insulin, whilst there are some practices achieving lower levels of good outcome using and more expensive insulin. The redesign of diabetes services has set out to address these issues.

5.5 Policy Framework

The national policy framework is the National Service Framework for diabetes, published in 2001. This sets out what action is needed in relation to diabetes nationally. Subsequently a set of NICE guidance has been issued which details how diabetes should best be managed.

Locally, diabetes is implicit within the NHS Rotherham five year plan (better health better lives) in relation to reducing morbidity and mortality from diabetes (and its complications) which will help to achieve their strategic outcomes of reducing ambulatory care sensitive hospital admissions and CVD mortality rate.

The NHS Rotherham redesign of diabetes services has also been underway to improve the services and care provided to Rotherham patients.

6 THANKS

The review group would like to thank the witnesses for their time, co-operation and willingness to engage in this process. Their contributions are gratefully acknowledged.

With special thanks to Dr Nagpal Hoysal, Public Health Consultant, NHS Rotherham, for his contribution and involvement in the review.

7 CONTACT

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