

DIABETES THINK TANK

Wednesday 9th July 2014

2.00pm – 4.00pm
Room S, Portcullis House

Patient experience

Meeting Report

Introduction

As a long-term condition, effective treatment of diabetes is critically dependent on a successful partnership between people with diabetes and their healthcare professionals. Therefore, a person with diabetes' experience of continued care from their diabetes service is paramount to the management of the condition.¹ To facilitate improvements for people with diabetes, it is important that the services providing diabetic care understand the priorities of service users.

As part of the National Diabetes Audit (NDA), a pilot Patient Experience of Diabetes Services (PEDS) survey ran between November 2013 and January 2014.

On the 9 July, the Diabetes Think Tank met to discuss how evaluating patient experience of diabetes care could help to drive improvements, in light of the publication of the PEDS pilot survey's findings. A discussion paper was circulated beforehand (containing seven questions set out in the annex), and focused on:

1. How best to capture patient experience data of diabetes care and what lessons can be learnt from the PEDS pilot survey
2. What can patient experience data tell us about how well people with diabetes are able to manage their condition
3. How best to use patient experience data to drive improvements in diabetes services

The discussion predominately focused on what potential benefits to people with diabetes could be gained by collecting patient experience data on diabetes services. The discussion also raised broader issues around self-management, particularly around the concern that there appears to be low numbers of people with receiving diabetes education.

Most notably the Think Tank was informed that plans to develop the PEDS survey into a full national rollout had been rejected by the Healthcare Quality Improvement Partnership (HQIP). The NDA will have to make a separate business case to HQIP to secure future funding for the survey. The Think Tank was told that the cost of a full-scale rollout had been estimated at between £50,000-£100,000. The Think Tank noted that the Friends and Family Test costs around £150 million a year.

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Summary of recommendations

The following three recommendations were agreed upon:

- The Think Tank agreed to work in partnership to help secure funding for a national roll out of the PEDS survey
- The Think Tank supported the use of financial levers, for example Commissioning for Quality and Innovation ('CQUIN') schemes to ensure that PEDS will have a high level of coverage
- The Think Tank supported an audit of the PEDS survey's first year results in order to help shine a light on areas where the experience of diabetes care can be improved, including education.

1. Patient Experience of Diabetes Services Survey

Background

A pilot Patient Experience of Diabetes (PEDS) survey ran between 13 November 2013 and 31 January 2014. The pilot was designed to trial and evaluate the PEDS survey ahead of its full-scale launch. The pilot survey was developed as a web-based tool, suitable for use by any GP or specialist diabetes service.

Discussion

The Think Tank discussed the form and content of the pilot survey. There was consensus that gathering patient experience data from people with diabetes could be an effective way of identifying the priorities of service users, and potentially a very useful tool for driving improvements in care. The discussion also explored the ways in which the PEDS survey could be refined to ensure the most reliable data possible was collected.

Key discussion points included:

- Some of the barriers to collecting reliable patient experience data:
 - **Identifying the NHS service from the data.** It is not always possible to link patient experience data back to the relevant NHS service
 - **Form and content of the survey questions.** Patients do not always respond honestly to questions that are too subjective, for example 'how confident are you...'
 - **Healthcare professional training.** It is possible that some older healthcare professionals may not have had the same focus on patient experience or personalised care planning during their training as some of the more recently qualified clinicians
- Recommendations for how to ensure patient experience data is useful:
 - **Ensuring that the data is representative.** It was acknowledged that the PEDS pilot survey may have predominately captured data from 'keen' patients and services, as it was an optional, pilot survey. It was agreed that it would be important to capture data from a full range of patients and services

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- **Asking the right questions.** The Think Tank noted that any future patient experience survey should contain questions designed to capture genuine patient experience, as opposed to being confined to a tick-box exercise, framed around ascertaining whether certain targets and standards have been met
 - **Area specific data.** The Think Tank also discussed the benefits of obtaining area specific patient experience data, to enable a comparison between areas and services
- How should patient experience of diabetes services data be collected?
 - **Real-time data.** The Think Tank considered the differences between capturing patient experience data in real-time versus collecting data on the whole system over a period of time
 - **Web-based tool.** The group discussed whether running the survey as a web-based tool was inclusive enough or whether it would discriminate against certain service users, for example, older patients

The Think Tank acknowledged that the PEDS survey was still in development but support for the aims of PEDS was unanimous. The merits of capturing immediate feedback from patients were generally agreed on and the Think Tank discussed some of the ways in which data from people with diabetes could be collected in real-time. However it was also noted that large scale, national patient experience surveys, collected over a specified period of time, are useful for generating an overview of the performance of services.

2. What insights into self-management can PEDS generate?

Background

Glucose, blood pressure and cholesterol control are essential in trying to avoid serious complications. However rates of achievement of the National Institute for Health and Care Excellence (NICE) recommended target ranges for these checks remain relatively low and vary significantly across the country. According to the National Diabetes Audit 2011-12, the percentage of people with diabetes achieving the target ranges for the checks were: ⁱⁱ

- HbA1c:
 - **27% of people Type 1 diabetes**
 - **66% of people with Type 2 diabetes**
- Blood pressure:
 - **52% of people with Type 1 diabetes**
 - **38% of people with Type 2 diabetes**
- Cholesterol:
 - **30% of people with Type 1 diabetes**
 - **42% of people with Type 2 diabetes**

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Discussion

The Think Tank agreed that the PEDS survey could generate important insights into people's own knowledge about how to manage their condition.

Discussion took place on to what extent PEDS can inform us about how people perceive their own ability to manage their diabetes: do they understand their condition and treatment; do they feel their engagement with health professionals supports them to manage their condition; and how engaged people with diabetes are in their care.

The key discussion points were:

- **Education.** The PEDS pilot survey findings suggested that only around **46% of people with diabetes had been offered a formal education plan**. Members discussed how there was not only an issue around how routinely clinicians offer an education programme to people with diabetes, but also with the uptake and attendance of those programmes
- **Complications.** The PEDS pilot survey findings suggested that **12% had no knowledge of how their treatment will affect their present and future health, with a further 29% saying that they had some knowledge but not enough**. Members discussed the difficulties of getting people to fully recognise how serious the complications of diabetes can be
- **Compliance with treatment.** The PEDS pilot survey findings suggested that only around **67% of people with diabetes feel confident about managing their diabetes**. Members discussed that compliance is a bigger problem than whether a person is hitting their treatment targets. Think Tank members stressed that it is important to identify the reasons behind poor compliance with treatment, for example: do people with diabetes fully understand how their treatment works; do they fully understand the implications of poor self-management; and are people with diabetes *able* to comply with their treatment

It was agreed that the PEDS survey has the potential to gain a better understanding of how well people with diabetes feel they are being supported by services, and crucially, it can give clinicians a unique insight into people's beliefs, understandings and fears about their treatment and self-management.

Specifically on the topic of structured diabetes education programmes, the Think Tank agreed that the PEDS survey could be a useful tool for holding services to account for how successfully they are supporting people with the right diabetes education. It was noted that it could also offer insight into the reasons why people do not always utilise the offer of diabetes education more effectively. It was noted that this is an area where there is lack of reliable data.

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3. How to use this information

Background

Patient experience measures can be embedded in the performance-management systems that guide the NHS. Data collected through the PEDS survey could in time, for example, be used in a range of ways to drive improvements:

- **Accountability.** Ensuring that people have a positive experience of care is one of the five domains of the NHS Outcomes Framework, which is used to hold NHS England to account for the performance of the NHS as a whole.
- **Incentives.** Some national financial incentive schemes – in particular through the Commissioning for Quality and Innovation ('CQUIN') schemes which links a proportion of provider's income to the achievement of local improvement goals – include good performance against patient experience measures. In the current 2014-15 financial year, the national CQUIN scheme is largely focused on driving up Friends and Family Test response ratesⁱⁱⁱ
- **Regulatory.** The Care Quality Commission (CQC) now uses a range of patient experience measures – particularly the National Cancer Patient Experience Survey – to determine the results of its investigations^{iv}

Discussion

The Think Tank discussed the variety of ways in which the PEDS survey could be embedded into existing incentive framework in the NHS. Members discussed how to make the most effective use of the data generated from the PEDS survey, to ensure that the measurement of patient experience is translated into improvements for people with diabetes.

The key discussion points were:

- **Financial incentives.** It was agreed that financial incentives are probably the most effective way to ensure the uptake of a PEDS survey locally. The Think Tank discussed the possibility of incorporating a measure of diabetes patient experience into the Quality and Outcomes Framework (QOF)
- **Glucose testing strips.** Members acknowledged that a shortage of glucose testing strips is still causing significant problems to many people with diabetes. It was suggested that the PEDS survey could include a measure to assess the availability of strips to hold services to account
- **Friend and Family Test.** Member discussed the possibility of including a measure of diabetes patient experience on the Friends and Family test, to capture real-time data of diabetes care
- **Hold services to account.** It was suggested that PEDS could be used as mechanism for highlighting poorer performing services

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- **Driving improvements.** It was suggested that the results of the PEDS survey could be displayed publically in a way which makes comparison of services possible, driving competition to make improvements

There was consensus that the PEDS survey has the potential to reveal useful data on diabetes self-management, specifically that it can highlight the barriers which people with diabetes feel are preventing them from meeting optimal treatment targets.

As a result, it was resolved that it is imperative that the PEDS survey is developed further so that it can be conducted on a national scale.

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List of attendees

Adrian Sanders MP	Chair <i>Diabetes Think Tank and All-Party Parliamentary Group for Diabetes</i>
Faye Edwards	Project Manager <i>Health Innovation Network</i>
Dr Rob Gregory	Chair <i>ABCD</i>
Dr Rowan Hillson	<i>Former National Clinical Director for Diabetes</i>
Paula Ireland	Quality Improvement Lead <i>EOE SCN</i>
Dr David Lipscomb	Consultant in Endocrinology and Diabetes <i>Eastbourne District General Hospital</i>
Professor Roger Gadsby MBE	Associate Clinical Professor <i>University of Warwick</i>
John Grumitt	Vice President <i>Diabetes UK</i>
Laura Fargher	National Diabetes Audit Engagement Manager <i>Diabetes UK</i>
Debbie Cook	Vice Chair <i>National Obesity Forum</i>
Benjamin Moody	Senior Public Affairs Manger <i>JDRF</i>
Lawrence Ambrose	Lead Policy Officer <i>College of Podiatry</i>
Dr Milan Piya	NIHR Clinical Lecturer in Diabetes and Endocrinology <i>University of Warwick and YDEF</i>
Katy Ingleby	Public Affairs Officer <i>JDRF</i>
Gemma Snell	Senior Project Manager <i>London Strategic Clinical Network</i>
Pauline Latham OBE	MP for Mid Derbyshire

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Melissa Holloway

Chief Adviser
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Dr David Hopkins

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Louise Brant

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Sanofi

Bill Morgan

Secretariat
Incisive Health

Beth Hooper

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Annex: list of questions posed

- Discussion question 1: Is the PEDS survey asking people with diabetes the 'right' questions? Will the data generated by the survey be a useful tool to drive patient-centred improvements in diabetes services?
- Discussion question 2: The PEDS survey is to be part of the National Diabetes Audit and so it is likely that it will be published annually. Is capturing this data in this way, rather than collecting it closer to 'real-time' (as with the Friends and Family Test) the most effective approach to obtaining useful data on diabetes patient experience?
- Discussion question 3: What conclusions is it possible to draw from the results of the pilot PEDS survey?
- Discussion question 4: How can healthcare professionals most effectively use the data generated from the PEDS survey, to ensure that the measurement of patient experience is translated to a driver of change?
- Discussion question 5: Could relevant measures from the PEDS survey be embedded into existing national financial incentives schemes, for example the Commissioning for Quality and Innovation (CQUIN) payment framework?
- Discussion question 6: What can patient experience data generated from the PEDS survey tell us about patient compliance and adherence with diabetes treatment?
- Discussion question 7: Can the PEDS survey highlight what barriers people with diabetes feel there are to achieving optimal targets for HbA1c, blood pressure and cholesterol?

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References

- ⁱ [National Diabetes Audit 2013-2014, Patient Experience of Diabetes Services Survey Pilot](#)
- ⁱⁱ [National Diabetes Audit 2011-2012, Report 1: Care Processes and Treatment Targets](#)
- ⁱⁱⁱ NHS England, 2014/15 NHS standard contract: CQUIN guidance, February 2014; available here: <http://www.england.nhs.uk/wp-content/uploads/2014/02/sc-cquin-guid.pdf>
- ^{iv} [Care Quality Commission, A new start: consultation on changes to the way CQC regulates, inspects and monitors care, June 2013](#)