

The Patient Experience Library

Insight Report

Young People and Diabetes

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Brighton University

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1. Introduction

1.1 About Insight Reports

There is no shortage of information on patient experience. Sources include CQC inspections, Healthwatch reports, Patient Opinion, Friends and Family Tests, NHS Choices star ratings and more. Making sense of it all can be very difficult - especially as the quality of some of it is questionable.

Our Insight Reports are based on in-depth trawls of the whole of the UK's evidence base on patient experience. Grading and analysis draws out high quality evidence to support scoping studies and deeper academic inquiry.

For this report, we found very little in the literature that describes young people's own experiences of living with diabetes, whether Type 1 or Type 2. We therefore focused on studies that describe young people's more general experiences of health services, and their levels of understanding of what constitutes a healthy lifestyle. We looked in particular at reports that covered food culture, nutrition and obesity, as these are important in the context of Type 2 diabetes.

1.2 About the Patient Experience Library

The Patient Experience Library brings together the whole of the UK's collective intelligence on patient experience, plus patient and public involvement. We have catalogued and indexed over 35,000 reports, including:

- Patient experience reports from health and care charities and think tanks
- Guidance on matters such as patient-centred commissioning
- CQC inspection reports and patient survey results
- All the reports from the local Healthwatch network
- Quality Accounts from health service providers
- Valuable archive materials from bodies such as LINK and the NHS Institute

For more about our work, please visit www.patientlibrary.net

2. Search results

2.1 Basic search

For our basic search, we trawled over 35,000 documents within the Patient Experience Library. Our searches yielded 651 results from sources including Healthwatch, the Care Quality Commission, government bodies such as the Dept of Health, NHS England, and NHS Improvement, plus national charities and think tanks.

We then applied relevance analysis and filtered out all reports with low relevance. That left us with 93 reports, which are listed alphabetically by title in the Appendix.

2.2 Graded search

We reviewed our 93 basic search results, to come up with a “top fourteen” reports list. We achieved this as follows:

Date: We filtered out any reports that were more than three years old

Maximum relevance: Applying relevance analysis a second time enabled us to narrow down to reports that looked specifically at young people and diabetes, as opposed to diabetes in general. We also focussed on associated topics such as diet and obesity.

Quality: It is generally acknowledged that the quality of patient experience reporting can be variable. Our shortlisted reports, in our opinion, demonstrate good quality, with work that is rigorous and credible, and with insights and solutions that could be replicable from one part of the country to another.

On this basis, our top fourteen reports (listed alphabetically by title, and with hyperlinks to the source documents) are:

Big Food Fight Quiz

Healthwatch Slough, Spring 2016

Children and Parents, Our Opinion, Food and Fitness

Healthwatch Lincolnshire, January 2016

Children and young people with long term conditions, what support is available for mental health and wellbeing?

Healthwatch Bradford and District with Barnardo's, January 2016

Eating Disorders and Body Image - Issues Affecting LGBTQ Young People

Healthwatch Northamptonshire, Aug 2016

Improving the Patient Experience of Children and Young People

Diabetes UK with 12 other charities, 2014

Improving young people's health and wellbeing. A framework for public health

Public Health England, January 2015

Maintaining a healthy weight and preventing excess weight gain among adults and children

NICE guideline, 13 March 2015

My diabetes, my care. People's experiences of community diabetes care and the support they are provided to self-manage their condition

Care Quality Commission, September 2016

Prevention of Diabetes in Bangladeshis in East London: Experiences and Views of Young People

Healthwatch Tower Hamlets, 2015

Report on Consultation on Healthy Alternatives to Junk Food - in partnership with NCS The Challenge

Healthwatch Wandsworth, 2015

Social and Cultural Aspects of Food Shopping. A pilot study of mums' healthy and unhealthy food choices

Healthwatch Essex, July 2016

State of the Nation 2016. Time to take control of diabetes

Diabetes UK

Tackling the causes and effects of obesity

Local Government Association, Jan 2015

The views of Children and Young People in Northamptonshire about Eating Disorders

Healthwatch Northamptonshire, August 2016

3. Key findings

This section presents key learning points drawn from the top fourteen reports. Findings are mostly **presented in the form of direct extracts from the reports**. All sources are referenced in the end notes.

Our main finding was that there is very little in the literature that describes young people's own experiences of living with diabetes, whether Type 1 or Type 2. Experiences of being diagnosed, of learning to self-manage the condition, of support from mainstream services or family and peers – these aspects are poorly described, if at all.

There are reports, however, that describe young people's more general experiences of health services, and their understanding of what constitutes a healthy lifestyle. The latter is particularly important in the context of Type 2 diabetes. We therefore focused on these sources of evidence, looking in particular at reports that covered food culture, nutrition and obesity. Within these topic areas, findings were as follows:

3.1 Diabetes in general

“The increase in the number of people with diabetes in the last 20 years has been unprecedented. It is more important than ever to ... help those who have been identified as at high risk of developing Type 2 diabetes to become healthier. When diabetes is not well-managed, it can lead to serious complications such as heart disease, kidney disease, stroke, amputations, and blindness. It is estimated that the NHS spends around £8 billion each year on treating these complications – most could be avoided or delayed by empowering people with the skills and

knowledge to manage their condition.”¹

“People from South Asian and Black communities are two to four times more likely to develop Type 2 diabetes than those from white backgrounds. People with a learning disability tend to have higher rates of obesity and therefore may be at greater risk of developing Type 2 diabetes. Both of these groups may also experience inequalities in their access to healthcare.”²

3.2 Diabetes and young people

Diabetes UK has produced a very good summary of the issues for young people with diabetes in its most recent “State of the Nation” report.³ Comments from other reports are as follows:

“Around 28% of children aged 2 to 15 were classified as either overweight or obese.

[The] obesity prevalence of the most deprived 10% of children is approximately twice that of the least deprived 10% (Health inequalities Public Health England). Children ... with disabilities are more likely to be overweight or obese. For children and young people, the support and encouragement of parents, carers and staff working in schools and clubs is vital in helping them to make good choices.”⁴

“In several areas, services identified barriers in engaging or reaching some groups of people to make sure they received the checks they need. Groups noted as being more difficult to engage with or monitor included younger people.”⁵

“There are significant variations in care for people with diabetes. Too often people with diabetes are not receiving the support they

need to help them manage their condition and reduce their risk of devastating and costly complications. It is the exception rather than the rule if young people receive all of their key checks.”⁶

3.3 Influences

3.3.1 Parents

A Healthwatch Essex “prototype study”⁷ looked at mothers’ healthy and unhealthy food choices while shopping. The study recognised that “everyday ‘foodways’ (i.e., our ways of doing food) are judged to be a major public health issue, with ‘unhealthy’ food choices considered a contributory factor in a range of chronic conditions, such as ‘obesity’, cardiovascular disease, type 2 diabetes mellitus and gastro-intestinal cancers.”

The study found that “The mothers had ... a desire to ‘treat’ members of their families with certain items, using food to express their care and maternal instinct (the food-shopping budget was often directed in favour of the likes and dislikes of their partners or children).”

The mothers “had a relatively good understanding of basic healthy foods, and tried to incorporate vegetables in their diet where they could; the problem thus seems to really lie in what they did not realise was unhealthy. For example, ‘Colman’s’ sauces, which were described as ‘lazy’ but ‘nutritious’, and the misinterpretation of fruit juice being a healthy alternative to fizzy drinks.”

A study by Healthwatch Lincolnshire (involving 1,100 people, including pupils from 20 primary schools and parents) identified that “very few parents cook with their child on a regular basis”, and “heard about a number of children who admitted to eating alone in their bedrooms”. The study found that “4% of children admit to not having any breakfast with a further 6% eating on the way to or at school.”⁸

3.3.3 Schools

Healthwatch Lincolnshire found that “Whilst around 95% of all people taking part in our surveys believe their school is a Healthy School, the evidence revealed from their responses suggests this is not the reality. Our results revealed that over a quarter of all children are getting less than the recommended guidelines of physical activity on a weekly basis, with more girls than boys not meeting this target.”⁹

The Lincolnshire study also asked about eating at school and found that “Almost a third of children (30%) either choose not to use the school dining area or dislike using it, although 82% of parents think they like to.”¹⁰

3.3.4 Local authorities

The Local Government Association states that “... local councils potentially have a significant role. Their decisions about how housing is planned, where green spaces and allotments are laid out, how well transport routes support cycling and walking, the leisure spaces and activities they provide and commission, their policies on licensing fast food, markets and other

food and drink outlets ... their influence on schools and places where children and young people gather - all of these make a significant difference to the extent to which the local environment is obesogenic or not.”¹¹

3.4 Effect on emotional wellbeing

Healthwatch Bradford asked young people about their experiences of living with long term health conditions including diabetes. They reported that “During our discussion with young people we heard how long-term conditions can have a significant impact on emotional wellbeing. Over half of the young people who completed the online survey told us their health condition had affected their life quite a lot or had a massive impact on their life.

Healthwatch asked young people: what do you think the ideal support for your physical and emotional wellbeing would look like? The overall feeling was the need for a mix of services which addressed the following issues:

- Making the link between physical and mental health; getting the right information
- Addressing waiting times
- Early intervention
- Environment
- Attitude and approach”¹²

3.5 Eating disorders and body image

Healthwatch Northamptonshire ran a survey¹³ on eating disorders, targeted at young people. Five times as many people responded to the survey as forecast. Findings included:

- More female respondents (84%) said they knew what an eating disorder was than male respondents (65%).
- 136 respondents (7%) thought they had an eating disorder and nearly one third (31%) of the respondents said they knew someone with an eating disorder.
- 53% of respondents did not know where to go for help with an eating disorder.
- Many respondents thought that there was a need for more education about eating disorders and awareness-raising.

Healthwatch Northamptonshire also spoke separately to LGBTQ young people about eating disorders and body image¹⁴, and found that “Speaking to this group highlighted issues that were different to those raised in our wider survey about eating disorders in young people. Issues mentioned included gender dysphoria and feeling uncomfortable in one’s body, body dysmorphia and body image issues specific to LGBTQ”. The interviewees wanted information about these issues as well as about eating disorders.

3.6 Diet and exercise

Healthwatch Slough ran a survey with young people from the Borough, focused on healthy eating. They found that when asked about lifestyle factors affecting health, “The majority of children (86%) referred to the influence of diet – perhaps to be expected given that the majority respondents had completed the questionnaire at the end of a healthy eating workshop. However, less than a quarter (23%) of the children mentioned exercise as a factor in keeping healthy. This is a concern, especially in the light of Slough’s high rate of child obesity.”¹⁵

Healthwatch Wandsworth asked shoppers at an Asda store about healthy alternatives to junk food. Shoppers were asked what is important when looking for somewhere to eat, and given three possible responses: “healthy, cheap, and tasty”. The overall response was that the most important aspect was healthy food, closely followed by the food being tasty and then cheap. However, when analysed by age, it was found that for under 25’s, the most important thing was that the food was tasty, followed by cheap and then healthy.¹⁶

Healthwatch Tower Hamlets talked to young people from the Bangladeshi community about diabetes. The inquiry found that “Young Bangladeshi people showed good knowledge of diabetes and its causes and have cogent ideas on its prevention. Participants were aware of diabetes being a major health issue. They were aware of the link between diabetes and poor diet. There was some knowledge about genetic risks and complications. Knowledge of diabetes was predominantly

gleaned from school. Participants recognised that the Westernised diets also increased risk. They felt they had greater knowledge and were more physically active than their elders. Views on prevention of diabetes were strong, including increasing diabetes awareness in schools, rewards for healthier lifestyles, reducing costs of exercise, reducing advertising of poorly nutritious foods and tackling the proliferation of fast food outlets.”¹⁷

3.7 Ways to help

“In their final message to PHE, one young person said ‘Asking for help is a massive thing for any young person. But adults seem to see it as a simple task. Please do something about it. It’s time that this changed. We need help’.”¹⁹

Diabetes UK has stated that “Much of what matters to adults will also matter to children and young people. The fundamentals of good care – and therefore a good quality experience of care – remain the same. However, there are some issues which will be particularly important for children and young people:

- 1. Communication:** healthcare professionals should use age-appropriate language and engagement corresponding to the developmental stage of the child or young person
- 2. Involvement:** the child or young person should be fully involved in decisions about their care with an ability to exercise choice and control
- 3. Mental health:** recognising the impact that treatment and care can have on a person’s mental health at a time when

their personality is developing, services should ensure that mental health issues are identified and appropriate psychological support is offered to patients and carers across the pathway

4. **Coordination:** care should be coordinated, ensuring that needs do not fall between different organisations
5. **Transition:** particular focus should be given to supporting people as they move from children's to adult services as well as from specialist into general care and importantly the monitoring of ongoing engagement with adult services
6. **Child and adolescent literacy:** services for children and young people should understand children and young people. All commissioners should challenge themselves to consider how the services they are designing would look and feel to the person using them

Appendix: Basic search list

The table shows results from our basic search, listed alphabetically by report title.

Title	Subtitle	Publisher
A Healthier Life For All - The Case For Cross-Government Action	An essay collection published jointly by The All-Party Parliamentary Health Group and the Health Foundation	The Health Foundation
A practical guide to self-management support, key components for successful implementation		The Health Foundation
A review of users' experiences of services for people with Eating Disorders in the East Riding of Yorkshire		Healthwatch East Riding of Yorkshire
Assessment on reducing health inequalities and the shared delivery plan 2015 to 2020		Department of Health
Banking on a Meal..		Healthwatch Lewisham - Healthwatch Bromley
Behavioural insights and health	Case Studies	Local Government Association
Behavioural insights in health care	Nudging to reduce inefficiency and waste	The Health Foundation
Better care in my hands, A review of how people are involved in their care		Care Quality Commission
Big Food Fight Quiz		Healthwatch Slough
Bristol Metropolitan Academy Healthwatch Workshops	Report	Healthwatch Bristol
Building the House of Care	How health economies in Leeds and Somerset are implementing a coordinated approach for people with long-term conditions	The Health Foundation
Can community-based peer support promote health literacy and reduce inequalities? A realist review		National Institute for Health Research
Children and Parents, Our Opinion, Food and Fitness		Healthwatch Lincolnshire
Children and young people with long term conditions, what support is available for mental health and wellbeing?		Healthwatch Bradford and District - Barnardo's
Children and young people's mental health - policy, CAMHS services, funding and education		House of Commons Library
Children and Young People's Participation Toolkit		Healthwatch Bradford and District - Barnardo's
Commissioning for better health outcomes		Care Quality Commission
Diabetes Clinic Results	Recommendations and Response	Healthwatch Luton
Diabetes in North Somerset (Diagnosis, Treatment and Support)		Healthwatch North Somerset
Diabetes Intelligence Report		Healthwatch Slough

Title	Subtitle	Publisher
Diabetes, The experience and provision of local services		Healthwatch Blackburn with Darwen
Diabetic Retinopathy Screening Service Q & A Report		Healthwatch Rochdale
Eating Disorders and Body Image - Issues Affecting LGBTQ Young People		Healthwatch Northamptonshire
Exercise, The miracle cure and the role of the doctor in promoting it		Academy of Medical Royal Colleges
Family Cooking Taster Session	Evaluation Report	Healthwatch Luton
Food journey at Calderstones	Calderstones Partnership NHS Foundation Trust	Healthwatch Lancashire
Frontline pharmacists	Making a difference for people with long term conditions	Royal Pharmaceutical
Growing healthy communities	The Health and Wellbeing Index	Grant Thornton
Head, hands and heart, asset-based approaches in health care	A review of the conceptual evidence and case studies of asset-based approaches in health, care and wellbeing	The Health Foundation
Health and Care of People with Learning Disabilities 2014-15		NHS Digital
Health and wellbeing needs of children, young people and families in Norfolk		Healthwatch Norfolk
Health inequality and the A&E crisis		Centre for Health Economics (CHE)
Healthwatch Engagement	Diabetes Support Group	Healthwatch Lewisham
Healthwatch engages with 1,600 Year 6 Pupils and 35 young disabled people at Crucial Crew		Healthwatch Herefordshire
Healthy beginnings, giving our children the best start in life		Local Government Association
Healthy Eating Research Project (CIB Project) - Final Report by BFA		Healthwatch Tower Hamlets - Bangladesh Football Association
Healthy High Streets Consultation, Summary Report		Healthwatch Merton
Helping people look after themselves, a guide on self-care		Local Government Association
Hospital food - the food journey		Healthwatch North Tyneside
Improving care for people with long-term conditions		Royal Pharmaceutical Society (RPS)
Improving the Patient Experience of Children and Young People		Diabetes UK with 12 other charities
Improving young people's health and wellbeing	A framework for public health	Public Health England
Learning (Intellectual) Disability, Getting it right for patients with a learning disability		Great Ormond Street Hospital for Children NHS Foundation Trust

Title	Subtitle	Publisher
Living longer, living well, How we can achieve the World Health Organization's '25 by 25' goals in the UK	A overview report by The Richmond Group of Charities	The Richmond Group of Charities
Living Well for Longer, One year on		Department of Health
Longer, healthier lives, but not for all	Annual Public Health Report 2015	Haringey Council
Maintaining a healthy weight and preventing excess weight gain among adults and children		NICE, National Institute for Health Care and Excellence
Management of adult diabetes services in the NHS, progress review inquiry		House of Commons Public Accounts Committee
Models of care for high-need, high-cost patients, an evidence synthesis		Commonwealth Fund
My diabetes, my care	People's experiences of community diabetes care and the support they are provided to self-manage their condition	Care Quality Commission
My Face, My Story (revised)	A creative art project gathering experiences of people with learning disabilities about accessing health and social care services	Healthwatch Hampshire
National Citizen Service (NCS) Healthwatch Workshops		Healthwatch Bristol
National mapping of weight management services, provision of tier two and tier three services in England		Public Health England
Nutrition Influence Study - Hospital Food Standards Panel Reference Group		Healthwatch Staffordshire
One hundred days for early action, time for government to put prevention first		Community Links
Our Rights project	Workshops Report	Claremont School, Council for Disabled Children/ National Children's Bureau and Healthwatch Bristol
Patients experiences of Hospital Food at Calderdale and Huddersfield Trust		Healthwatch Kirklees
People-driven care	Conference 2016	Healthwatch Newcastle
PHOENIX, Public Health and Obesity in England - the New Infrastructure Examined	Second interim report	PRUComm
Poor beginnings, health inequalities among young children across England		National Children's Bureau
Prevention Of Diabetes in Bangladeshis in East London	Experiences and Views Of Young People	Healthwatch Tower Hamlets
Priorities for mental health	Economic report for the NHS England Mental Health Taskforce	Centre for Mental Health
Report on Consultation on Healthy Alternatives to Junk Food - in partnership with NCS The Challenge		Healthwatch Wandsworth

Title	Subtitle	Publisher
Report on Primary School Nurse Service Pilot Project		Healthwatch Trafford
Report on services and support for people with Diabetes and those who are yet to be diagnosed		Healthwatch Wirral
Review of health services for Children Looked After and Safeguarding in Devon		Care Quality Commission
Review of health services for Children Looked After and Safeguarding in Sandwell Metropolitan Borough		Care Quality Commission
Review of the Diabetic Retinopathy Screening Programme		Regulation & Quality Improvement Authority (RQIA)
Self-Care Matters 2016		Healthwatch Bromley - Healthwatch Lewisham
Social and Cultural Aspects of Food Shopping	A pilot study of mums' healthy and unhealthy food choices	Healthwatch Essex
State of the Nation	Challenges for 2015 and beyond	Diabetes UK
State of the Nation 2016		Diabetes UK
Tackling the causes and effects of obesity		Local Government Association
The future of child health services, new models of care		Nuffield Trust
The management of adult diabetes services in the NHS, progress review		National Audit Office
The role of allied health professionals in public health, examples of interventions delivered by allied health professionals that improve the public's health		Public Health England
The views and experiences of children, young people and parents using health and social care services in Waltham Forest (updated)		Healthwatch Waltham Forest
The views of Children and Young People in Northamptonshire about Eating Disorders		Healthwatch Northamptonshire
Tier 4 CAMHS at Riverside		Healthwatch Bristol
Understanding the health and wellbeing needs of looked after children, young people and adoptive families		Healthwatch Norfolk
Understanding Young People's Experience of Mental Health and Wellbeing	Engaging with the Thomas Gainsborough School	Healthwatch Suffolk
Update on hospital food		Healthwatch North Tyneside
Visit Report	The Hive Youth Club	Healthwatch Bristol
Visit to City of Bristol College, Hengrove Site		Healthwatch Bristol
Vital signs	Taking the temperature of health and care services for people living with long term conditions.	The Richmond Group of Charities

Title	Subtitle	Publisher
What will make a difference for people in Slough living with a long term condition?		Healthwatch Slough
Whole in one	Achieving equality of status, access and resources for people with depression	2020health
Young Healthwatch meeting summary	City Hall	Healthwatch Bristol
Young People's Healthwatch	Paediatric Menu Tasting Event	Healthwatch Kingston upon Thames
Young People's Question Time Event		Healthwatch Sheffield
Young People's Views of Sexual Health & Mental Health Services	A 'True Talk' event delivered by Healthwatch Central West London and Youth Projects International	Healthwatch Central West London
Young Voices, Your Story, Your Health		Healthwatch Rochdale

References

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- 3 State of the Nation 2016. Time to take control of diabetes. (Pages 29-30). Diabetes UK
- 4 Maintaining a healthy weight and preventing excess weight gain among adults and children. NICE guideline, 13 March 2015
- 5 My diabetes, my care. People's experiences of community diabetes care and the support they are provided to self-manage their condition. Care Quality Commission, September 2016
- 6 State of the Nation 2016. Time to take control of diabetes. Diabetes UK
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- 8 Children and Parents, Our Opinion, Food and Fitness. Healthwatch Lincolnshire, January 2016
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- 11 Tackling the causes and effects of obesity. Local Government Association, January 2015
- 12 Children and young people with long term conditions, what support is available for mental health and wellbeing? Healthwatch Bradford and District with Barnardo's, January 2016.
- 13 The views of Children and Young People in Northamptonshire about Eating Disorders. Healthwatch Northamptonshire, August 2016
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- 15 Big Food Fight Quiz. Healthwatch Slough, Spring 2016
- 16 Report on Consultation on Healthy Alternatives to Junk Food - in partnership with NCS The Challenge. Healthwatch Wandsworth, 2015
- 17 Prevention of Diabetes in Bangladeshis in East London: Experiences and Views of Young People. Healthwatch Tower Hamlets, 2015
- 18 Improving young people's health and wellbeing. A framework for public health. Public Health England, January 2015.
- 19 Improving the Patient Experience of Children and Young People. Diabetes UK with 12 other charities, 2014