

20 years of successful improvements



NDR

**NATIONELLA
DIABETESREGISTRET**
SWEDISH NATIONAL DIABETES REGISTER

Figure: Blood Pressure <140/85 mm. Hg among patients treated with antihypertensive drugs. Primary care (n=384 124).

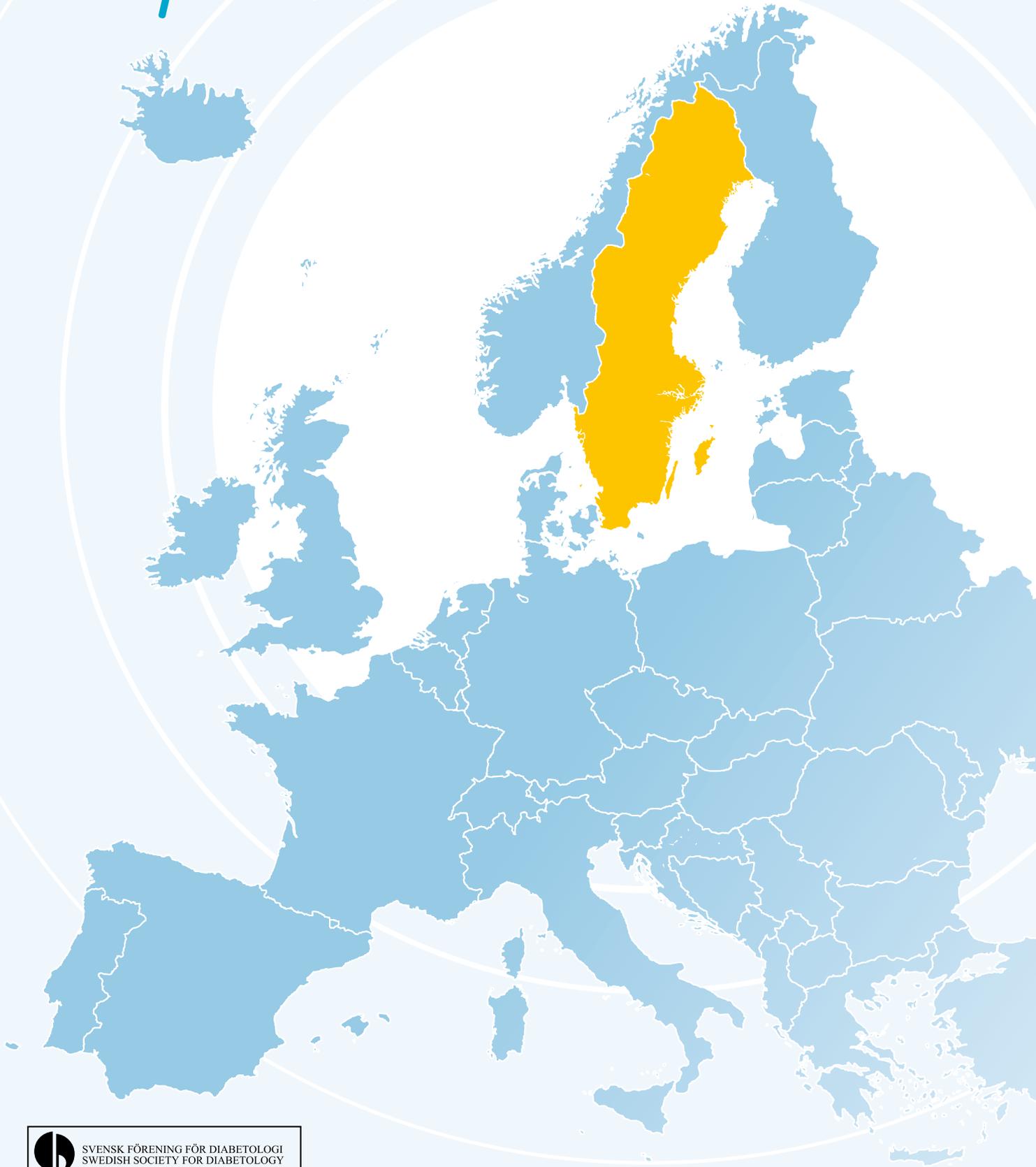


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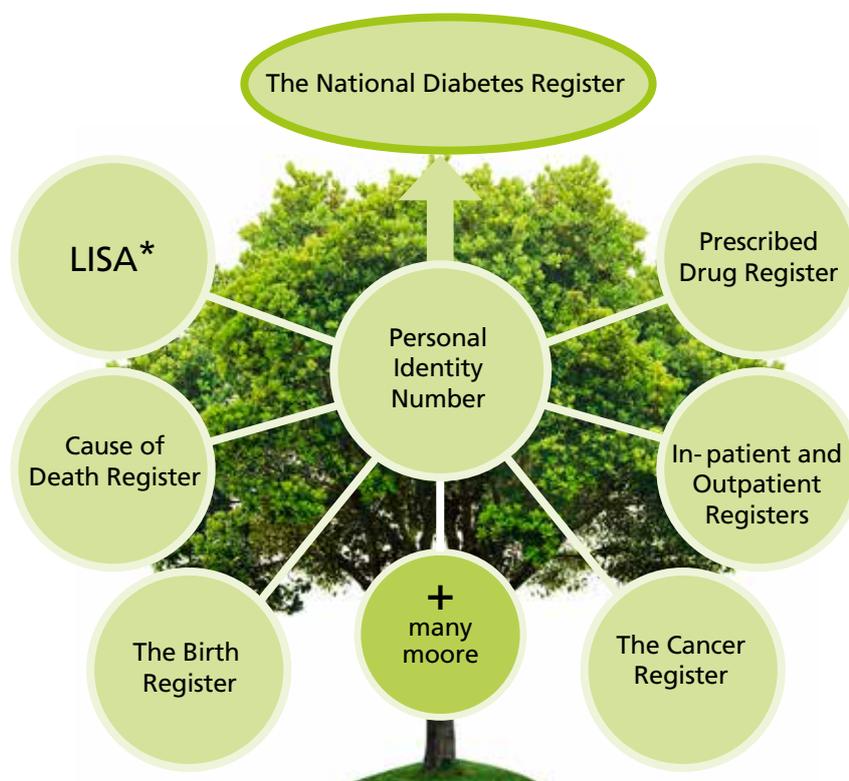
The NDR at 20 years

How the NDR got started

The Saint Vincent Declaration emerged from a 1989 meeting that included diabetologists and experts, as well as representatives of patient organisations and the various European governments. The objective of the conference was to identify ways of easing the burden of diabetic complications. One of the key recommendations was to "establish monitoring and control systems using state-of-the-art information technology for quality assurance of diabetes health care provision and for laboratory and technical procedures in diabetes diagnosis, treatment and self-management." ¹

The National Diabetes Register (NDR) was launched following negotiations between specialists, medical professionals and patients. Initial patient data were entered in 1996. The parameters were baseline clinical characteristics, risk factor control indicators, presence of diabetes complications and ongoing treatment. The approach facilitated continuous quality assurance, as well as comparisons of the results generated by the various clinics with national averages.

Specialist clinics, which primarily reported patients with type 1 diabetes, were the most active at first. Since 2000, however, data on type 2 diabetes have accounted for most of the steady increase. Online reporting, along with direct transmission from patient chart systems in recent years, have provided the technical infrastructure.



The Swedish personal identity number system permits the various national databases and quality registers to link and share the type of information required to conduct rigorous scientific studies.

* Longitudinal Integration Database for Health Insurance and Labour Market Studies.

The NDR in 2016

Evidence-based national guidelines have been drawn up for diabetes care. The NDR enables monitoring of the degree and effectiveness with which the guidelines are being implemented. Quality assurance is integral to successful care at the local, regional and national levels alike. Traditional Swe-

dish confidence in national treatment standards, along with the publicly funded healthcare system, smooths the way for that kind of effort.

The NDR has been organisationally incorporated into the Centre of Registers of the Western Sweden Region, which provides co-funding along with the Swedish Association

¹ Diabetes care and research in Europe: the Saint Vincent declaration. 1990 May; 7(4):360

DATA

>500,000 patients!
Many variables...

Demographics	Treatments
Socioeconomic status	Management
Ethnicity, profession	Complications
Biomarkers	Other disease
Risk factors	PROM

and many more...



OPPORTUNITIES

Improve care
Observational studies

ASCERTAINMENT

95% typ 1 DM.
90% typ 2 DM.

of Local Authorities and Regions. Among Centre of Registers employees are those who devote all of their time to the NDR, as well as statisticians and engineers who develop and maintain other national quality registers as well. The NDR steering committee consists of a scientific advisory board and representatives of the organisations that launched the register. Members of a working group compile an annual report and promote discussion of ways to improve the NDR. They also conduct most scientific studies, often in collaboration with other experts and teams of researchers, as well as national and international networks.

The research areas now include almost all facets of diabetes care, including patient-reported outcome measures and pharmacoepidemiology. The Swedish personal identity number

system permits the various national databases and quality registers to link and share the type of information required to conduct rigorous scientific studies, all of which are subject to strict confidentiality requirements and approval by an ethical review board.

Conclusion

The NDR has become indispensable to Swedish diabetes care, promoting patient benefit in several different ways. Monitoring the performance of clinics from year to year for comparison with national and regional averages is still the most important function of the register. Following up on guideline compliance, treatment and complications are equally important at the national level. Scientific studies that proceed from data in the NDR, other national databases and registers supply vital

insights into the personal and social consequences of diabetes and offer a vehicle for evaluating procedures and treatment strategies at multiple levels. ■

The NDR has become indispensable to Swedish diabetes care, promoting patient benefit in several different ways.

Advancing diabetes care

The NDR's Soffia Guðbjörnsdóttir outlines some of the challenges involved in establishing the register, as well as some of the achievements thus far and the potential for further advances.

The World Health Organization (WHO) reveals that there are some 60 million people with diabetes in the European Region, or about 10.3% of men and 9.6% of women aged 25 years and over. Prevalence of diabetes is increasing among all ages in the European Region, mostly due to increases in overweight and obesity, unhealthy diet and physical inactivity.

Worldwide, high blood glucose kills about 3.4 million people annually. Almost 80% of these deaths occur in low and middleincome countries, and almost half are people aged under 70 years. WHO projects diabetes deaths will double between 2005 and 2030.

In Sweden, the healthcare community has worked to devise a National Diabetes Register (NDR), which, through collating and sharing patient information, is making great progress at not only revealing some of the gaps which exist in current care pathways, but also at enhancing the level of diabetes care being provided. Here, the NDR's Soffia Guðbjörnsdóttir outlines some of the challenges involved in establishing the register as well as some of the achievements thus far and the potential for further advances.

What are the origins of the register, and how does it respond to issues raised in The Saint Vincent Declaration?

The register was started by members of the healthcare profession working in the area of diabetes in Sweden who were very much influenced by the Saint Vincent Declaration, which highlighted the need for better diabetes care. From the discussions that were held and an evaluation of the current landscape it was decided that a National Diabetes Register was a logical step towards achieving this.

It took a number of years to get started, with a lot of pioneering work going in to the foundations of the register, which included putting together the questionnaire and bringing the somewhat diverse elements together to form a coherent whole. Once this had been achieved, the register formally started in 1996, and has been growing ever since.

What challenges have you experienced since the register's inception?

Perhaps the biggest challenge – aside from ensuring that the register actu-

ally worked – was in educating people as to the power of the system, and the potential it has to enhance the level of patient care. A significant part of this was to demonstrate it was not just another register in which a person's data would be inputted and would then disappear and remain inaccessible. The NDR was set up to be a resource which could be used and accessed by all.

We also had to work to the doctors, clinicians and nurses working in the field of diabetes, as well as with those with diabetes, to show them that the NDR is an important and useful tool which, if properly used and accepted by all the actors involved, can help us to significantly improve diabetes care. Here, it was important for us to ensure that the registration process was as smooth and seamless as possible so that it would not be seen as an extra burden on workloads and so detract from the time that healthcare professionals have to spend with their patients. In addition, there is also an ongoing dialogue with all of those who have an interest in providing better diabetes care, and this input serves to help make the registry evolve in

a more organic way. This has indeed been a challenge, and the online feedback has been a great help here.

What have you learnt from the online feedback?

We have learnt a lot which has helped us to improve. The data we gathered as a community is brought together; we look at it and we understand it together. It is here where perhaps the most significant lesson has been learnt: the open discussion that the register has enabled means that we are now aware of what we are doing, how we are doing it, and what remains to be done. All of this is tailored towards one end goal: to do things in a better way and to improve diabetes care, and we can do that by understanding your own data and understanding the variations.

How is the registry enabling new and better research?

The registry was not designed to be a research database. The aim was, and still is, to assist the development of better diabetes care. However, that has evolved and as the registry has grown – today we have almost complete data – so we must use the database for research, it would be unethical not to do so.

The research began slowly, and we produced several descriptive articles designed to demonstrate the differences between hospitals etc. and the gap between reality and guidelines, which was great as a basis for discussion. As the register has become increasingly stable, we are now able to do proper observational studies. That is because we can cross link to other databases, meaning that we have information on all patients from a lot of other registries and so are able to follow them to better understand what good metabolic control really means.

Alongside this we have also now produced several important scientific



SOFFIA GUÐBJÖRNSDÓTTIR

Professor, Director of the Swedish National Diabetes Register

PHOTO: CHARLOTTA SJÖSTEDT

publications, such as, for example, one in the New England Journal of Medicine (NEJM) about excess mortality in Type 1 diabetes, as well as another in the British Medical Journal (BMJ) about the positive effect associated with insulin pump treatment. These papers are just two examples of important scientific publications which have stemmed from the registry and which have led to a lot of discussion, not only in Sweden, and which in turn will lead to improved diabetes care.

Do you feel that there should be more efforts to try to join up different national plans and registers across the EU?

For improvements to take place, the ability to compare data is an absolute necessity. Of course, everyone involved wants to do their best and wants to produce the best possible results and provide the best possible level of care, and this cannot be done by working from a single data set alone; to really drive improvement data must be compared and, moreover, must be followed over time. Quality registries are integral to this.

How much of an issue is data protection?

This is extremely important and is something that we take very seriously. In Sweden there is an organisation for quality registries, as well as a patient law and legacy which we follow and abide by. Of course, we always ensure that all data cannot be linked back to a specific patient.

People in Sweden have a level of trust in registries and the data contained therein which perhaps does not exist in other countries – at least not to the same extent. Those involved in or aware of initiatives such as the NDR know that they are a valued and valuable tool, and that we are able to learn a lot from them to improve services. As such, there is very little scepticism,

and very few people are concerned that their data will be insecure.

Has this included the involvement of patient organisations?

The Registry's steering group contains a representative from the patient organisation, and we co-operate with them at every level; we listen very carefully to their needs, their thoughts

this, of course, may not only be a result of data protection breaches, but also of laws in some countries which make the establishment of such registries very difficult things to achieve.

The NDR is a very simple thing, and was purposely designed that way. We included as few indicators as possible, and we ensure data is secure and that we are in total agreement

One of the main benefits of the register is that we know what we are doing; we know more about who is at risk, where we can improve and so on.

and we work on projects together. The patient organisation is currently very interested in creating the capacity for every patient to be able to log in and see their own data online. Currently, patients are able to ask their clinic for a copy of their data – something we recommend – the next step will be for patients to be able to check their own data and follow it by logging in online.

How have you judged perceptions of the register from those outside of Sweden, and do you think that there are elements of the registry which could be exported to other nations?

Often when I travel outside of Sweden to discuss the registry, people are surprised that it works the way it does, and that everyone can see data from the different hospitals and clinics. This perhaps goes back to the argument that there is a level of trust in Sweden with regard to data protection which might be different elsewhere – and

that this is the best way to improve diabetes care. What is more, we work closely with the patient organisation to ensure that we are only including the things which patients feel they want to include. When that is done correctly, data protection becomes less of an issue – although that is not to say that it should not be ensured at all times.

Aside from the patient organisation, have the medical community been open to the establishment of the NDR?

It took some time for the NDR to become widely accepted. One of the main reasons for this was a perception on the part of many doctors and clinicians involved in diabetes care that mixing cases would mean that comparisons would be impossible. While that may be true in some instances, it is a problem that can be, and has been, overcome. We achieved this by making sure that people know their own data, and that they know their own

case mix. We have some indicators of case mix, and it is important to have a comparison so that you can identify trends.

Following on from this, we have not experienced any significantly negative responses to the NDR from the medical community. Openness is the key to making the registry a success; you have to know your own data and be able to answer questions about it, and that will all help you to identify any problems as well as to identify things which could be done differently.

How has the registry informed work elsewhere, such as the European Guidelines?

Sweden's national guidelines are very similar to those which have been developed at the European level, and the registry has always worked towards the same end, with its targets and so on all put together according to the guidelines so that they go hand in hand.

Given that, as you have mentioned, the registry began in 1996, what do you feel have been the main gains so far?

One of the main benefits of the register is that we know what we are doing; we know more about who is at risk, where we can improve and so on. Furthermore, we are now beginning to analyse trends in hard end points like mortality and CVD, and while we can't say that the registry is solely responsible for that it has certainly played a role. The register is also making it possible for people – such as those who have children with diabetes for instance – to see the differences between regions when it comes to diabetes care, and this helps us to work towards a more equal playing field. It is extremely important to measure the gap between different clinics and different ends of the country as well as the gap between guidelines and reality.

What are your aims and goals moving forwards?

One aim is to have automatic data transfer from electronic medical records directly into the registry. We have that in about 60% of the registry today, while the remaining 40% requires double entry. We want to increase this to 100% online transfer.

Another very important aim is to add patient reported outcome measurements, which is an ongoing project involving patient questionnaires. A further goal is to enable patients to have automatic access to their own data and be able to view their records online.

Regarding research, the data collected is growing, and the followup period is getting longer and longer. We can now follow children with diabetes up until adulthood and, in the future, that will give us a better understanding and thus improved care.

People in Sweden have a level of trust in registries and the data contained therein which perhaps does not exist in other countries – at least not to the same extent.

Will funding be an issue due to the long term nature of the follow-ups?

The registry is not expensive. Of course, financial support is needed, but this is not substantial, and in Sweden the registry is a part of clinical care, so I don't think that funding will be an issue for us in the future. ■

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“The Button”

– an online tool that makes diabetes data available to everyone

The National Diabetes Register took a giant leap forward towards transparency in 2014. Up-to-the-minute online data on diabetes care became accessible to anyone who was interested. The Button tool (in Swedish: Knappen) permits instant insight into the degree to which health centres, hospitals and outpatient clinics are meeting their targets.

The tool provides endless opportunities for you to quickly and easily make your own selection among a wealth of data. You can examine how well various counties, health centres, hospitals and outpatient clinics have met their targets over time. You can compare facilities all the way down to the health centre level. You can customise your own indicators and specify your own periods. You can select your population sample based on gender, age or type of diabetes.

The register had previously presented transparent data about both counties and outpatient clinics. The Button extends that capability to individual health centres. The overall response

has been highly favourable. Professionals are aware that the composition of patient groups and other parameters varies considerably. Register data cannot be used to rank healthcare providers and facilities. But providers can analyse their performance in order to identify areas for improvement. They can also learn from others and pull themselves up by their own bootstraps.

Patient organisation waxes enthusiastic

The Swedish Diabetes Association is wildly supportive of the Button.

“We view this as a giant leap forward for promoting frank and open

Just one click to start improvement work!



discussion,” says, Fredrik Löndahl, President of the Swedish Diabetes Association. “Our local branches have started using the Button to obtain data that they can use in patient advocacy efforts.”

We view this as a giant leap forward for promoting frank and open discussion.

The local branches are also discussing care quality issues with regions and county councils. The availability of data at the health centre level has set the stage for a whole new level of deliberations.

Mr Löndahl has not seen any indications that individual patients are using the Button to choose health centres for themselves. That is not the purpose of the Button and the Diabetes Association does not recommend that it be used that way.

The Button permits a clinic to see all of its outcomes and monitor them over time. A single click or tap is all that is needed to download images of graphs for subsequent incorporation into PowerPoint presentations at diabetes team care conferences. Information about specific groups of patients is also available by logging in to the National Diabetes Register, though not through the Button. For instance, the user can find out what patients have been overlooked when appointments were scheduled. You can also identify those that need special interventions due to hypertension,

high blood glucose levels, etc.

Employees of the register have received a number of reports that the Button is a popular tool.

“Many people, particularly those engaged in improvement efforts at the county council level, are extremely pleased by the Button,” says Soffia Guðbjörnsdóttir, who is in charge of maintaining the register. “And the outcomes of the counties that have started using it are clearly heading in the right direction.” ■

Check out the Button at nдр.nu/knappen



FREDRIK LÖNDAHL, President of the Swedish Diabetes Association, says that the Button represents a giant leap forward.

PHOTO: SWEDISH DIABETES ASSOCIATION

The small diabetes team with great ambitions rise

The last thing they want is to stick their heads in the sand. If a patient suffers a setback, they do something about it. Now. They don't wait until the divorce is final or the broken leg has mended. They are proactive, creative and goal oriented.

Diabetes nurse Ingela Sager talks about her diabetes team at Läkargruppen Mölndalsbro, a small health centre on the outskirts of Gothenburg that sees approximately 8,400 patients every year. She and Dr Inger Wallin are the backbone of the team. At one time the members had high expectations but lacked a clear strategy for translating them into reality. That all

changed when the team participated in an NDR IQ improvement project sponsored by the National Diabetes Register (NDR) from November 2012 to May 2014.

The whole diabetes team took off for Stockholm with the goal of acquiring systematic improvement skills along with their colleagues at other health centres. The immediate

objective was developing the ability to analyse the problems they were experiencing and identify the root causes. In between sessions, the participants returned home and applied the information and insights they were acquiring to clinical practice.

“One day the pieces fell into place,” Ms Sager says. “We were still a little fuzzy about how everything fit together, but a little diagram made all the difference.”

The exercise involves drawing a diagram that resembles fish bones. The purpose is to progressively deconstruct and analyse the dynamics of clinical approaches that are not working.

Learning to communicate more effectively with patients

Ms Sager had the sense that she and some of the health centre's patients were talking above each other's heads. The team concluded during the training sessions that they did not have enough advance communication with patients about the purpose of their appointments. Other health centres had run into the same challenges and found solutions that Ms Sager and her coworkers were able to use. Now patients receive a questionnaire that they fill out and bring along to the appointment. The questions address their treatment regimen, activities of daily living, diet, exercise, smoking habits, etc.

“We get off to a much better start this way,” Ms Sager says. “We have a better feeling for each patient as a



Ingela Sager, R.N., and Inger Wallin, M.D., have learned a method of identifying the processes in clinical practice that are not working the way they should. Here they draw fish bones diagrams. PHOTO: PAUL BJÖRKMAN

s to new levels

whole person, and they are empowered to understand why we are performing the various tests and examinations that we subject them to.”

Ms Sager empathises easily and can be swept along in a patient’s troubles. Her new awareness allows her to maintain her focus on diabetes care and a healthy lifestyle no matter what is happening in a patient’s life. The way it used to be, she might downplay the importance of glycaemic control if someone was in the process of grieving, had a broken leg and was unable to exercise, etc. Nowadays she looks for alternatives that will help a patient endure a crisis without their glucose levels going through the roof.

Everyone gets in on the act

Better communication with patients has not been the only priority. Expansion of the diabetes team also provided a needed boost. And the staff of the entire health centre has picked up on the new energy. Turnover is low and communication has always been good. Easy for the diabetes team to get all coworkers involved in the improvement process.

“That was just a matter of going with the flow,” Ms Sager says. “But there has also been a ripple effect. Others on the human resource team are drawing their own fish bones now.”

One concrete result of greater coordination is the emergence of clear uniform instructions for taking various kinds of blood tests. No longer is there any doubt that each member of the staff is responsible for identify-

ing potential issues that patients are facing, regardless of when and where they manifest. A patient is given the same target values to strive for regardless of the team member who is involved at the time.

“The mixed signals were confusing our patients,” Ms Sager says. “These days everyone is on the same track.”

Better results in the National Diabetes Register

Due to the changes that the health centre has adopted, its performance in the NDR has improved.

“The biggest effect showed up at the beginning,” Ms Sager says. “Our blood pressure and glucose levels have relapsed a little since then. Progress is a never-ending struggle.”

Ms Sager checks the NDR for the health centre’s performance a couple of times a week and thinks that the team has a much better overview of trends now. The initial transition to new working methods demanded a great deal of time. Once that phase had passed, the most pronounced impact is greater efficiency and focus.

The team has embarked on a number of other improvement efforts. An initiative is already under way to better support patients with diabetes who have serious mental illness. The shortest and most effective path to making sure that will happen is to collaborate directly with patients and their psychiatrists. The team also launched an experiment to improve the lives of obese insulin resistant patients. An app collects data on their

diet, blood glucose levels and exercise habits.

“Change is what makes the world go round,” says Ingela Sager. “You can’t rest on your laurels if you want your patients to receive the best possible diabetes care.” ■

Ninety-nine diabetes teams learn systematic improvement methods

In 2003, the National Diabetes Register launched a series of improvement projects under the umbrella name of NDR IQ. Each project lasts for 18 months. Diabetes teams train in the methodology and apply what they have learned to clinical practice. The training teaches participants to analyse their day-to-day processes and pinpoint the root causes of the difficulties they are facing. The teams design action plans and adapt their processes under supervision. They also get together to engage in group discussions and share their experience. They incorporate the habit of monitoring their performance in the NDR and tracking changes into their standard routines. A total of 99 diabetes teams with 43,600 patients have taken part in NDR IQ projects.

Most people with diabetes struggle hard to maintain good glycaemic control but not all of them succeed. A national programme on behalf of those with HbA1c levels above 70 is now under way.

New options for patients with HbA1c over 70

Katarina Eeg-Olofsson is a senior consultant at the diabetes clinic of Sahlgrenska University Hospital. She frequently sees patients who have difficulty providing the kind of self-care that diabetes demands. Often the problem is that their blood glucose levels are difficult to control. Comorbidity or personal challenges may be aggravating the situation. Some patients are capable of caring for themselves but fail to make it a priority. They are not experiencing any discomfort and family and career are consuming all of their time.

“We devote major effort and resources to certain individuals and sometimes we feel like giving up,” Dr Eeg-Olofsson says. “We are not getting anywhere.”

In 2014, she and her colleagues launched a project for patients with high HbA1c levels. The background

was a nationwide initiative for patients with high HbA1c over 70 mmol/mol, by the National Programme Council for Diabetes at the Association of Local Authorities and Regions.

Training and frequent communication

The diabetes team at Sahlgrenska University Hospital scoured its medical records for all patients with diabetes type 1 and HbA1c over 70. The team decided to prioritise younger patients and those with very high levels of HbA1c. Each of the eight doctors and six nurses on the team picked five individuals who were invited to participate in the project. The patients had to be willing to set aside time and be responsive to change. They are offered training and frequent communication with diabetes caregivers for up to six months. They also qualify



KATARINA EEG-OLOFSSON, consulting physicians at the diabetes clinic of Sahlgrenska University Hospital, has discovered that certain initiatives work well for patients with HbA1c levels over 70.

PHOTO: CHARLOTTA SJÖSTEDT

for continuous glucose monitoring (CGM) or Libre, a new continuous meter. Both methods measure glucose levels in tissue fluid by means of a sensor on the skin. Some patients have declined to participate. Those who accept begin with an analysis of their situation. What is preventing them from lowering their HbA1c levels? What openings for improvement do they see? Each individual has a different answer.

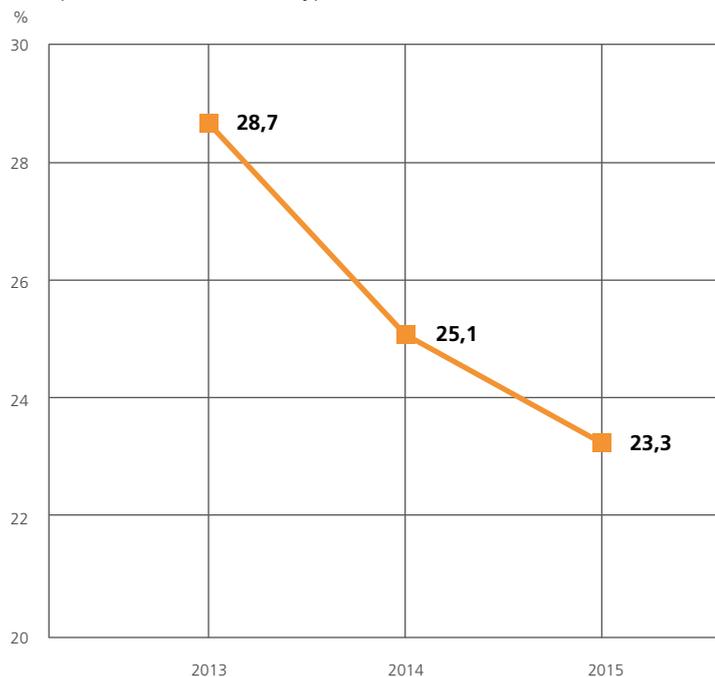
It is still too early to evaluate, but everyone who has been followed up after three months has attained a lower HbA1c level, whether significantly or minimally so. The Libre meter appears to have had a crucial impact on the results. It is easy to use and displays a rolling eight-hour report. “All of a sudden you can see your patterns in the form of a curve,” Dr Eeg Olofsson says. “It’s like, ‘Aha, that’s what happens when I have bread and cheese for breakfast. And just look at what granola does.’ It’s a whole new way of learning by visualising what is going on.”

She is very pleased that something can actually be done to help these patients.

“So far it doesn’t seem to be diverting our resources from other patients. On the contrary, we are in a better position to provide effective services for everyone.” ■

“It’s like, ‘Aha, that’s what happens when I have bread and cheese for breakfast. And just look at what granola does.’ It’s a whole new way of learning by visualising what is going on.”

Percentage of individuals with HbA1c over 70 mmol/mol.
Special clinics, Diabetes type 1



Time for patient's to be resound more clearly in the National Diabetes Register

The Register's patient questionnaire will make it easier for diabetes teams to make correct decisions on behalf of and together with the individuals they work with. The questionnaire will also serve as a new tool for improvement efforts and research. Gradual implementation of the questionnaire will begin in 2015.



voices

How are you doing, and what is happening with your diabetes? How well is the support you are receiving from diabetes caregivers working? That is a broad overview of the topics that the questionnaire covers. It will be distributed electronically and patients will fill it out prior to appointments with doctors and nurses. The results will permit an assessment of areas that require greater focus.

Hospitals and clinics will be able to use the findings in their improvement efforts, as well as in evaluating training programmes, new medical devices and other initiatives to benefit patients. New research horizons will open up as well. Design of the questionnaire has required the contributions of many experts over the course of several years. According to Soffía Guðbjörnsdóttir, who is in charge of maintaining the Swedish national Register, the project has been more difficult than starting the entire register way back at the beginning. Nobody had put together this kind of questionnaire before. The trick was to identify questions that pinpoint what is important for patients themselves, not what caregivers happen to believe. Among the no-no's were questions

Can I do whatever I want despite having diabetes?

that imposed guilt, violated a patient's privacy, or were superfluous, ambiguous or difficult to grasp. Capturing changes over time – new medical devices, major life events, etc. – was also essential.

Thorough effort completed

After several initial attempts to make some headway, Maria Svedbo Engström, a PhD student at Dalarna University, was assigned the task of taking over from the ground up. She conducted in-depth interviews with 29 individuals who had diabetes to find out what they considered important. The thorough analysis that followed led to a preliminary set of questions. The questionnaire has been revised a number of times in consultation with various types of experts, the patient organization the Swedish Diabetes Association, doctors and nurses within diabetes care.

“Quality trumps speed in this particular case,” Ms Svedbo Engström says.

The questionnaire has been tested in a number of different ways. For instance, some of the original interviewees responded to the questions while thinking out loud. That way Ms Svedbo Engström could quickly identify wording that was difficult to understand or conducive to misinterpretation.

The Diabetes Association has pushed the project and been critical of the delays.

“But we realize that the material

has been meticulously compiled,” says Fredrik Löndahl, Chairman of the Association. “I am absolutely certain that these are the right questions to ask.” ■



MARIA SVEDBO ENGSTRÖM at Dalarna University conducted in-depth interviews with 29 individuals who had diabetes in order to find out what they considered important. The interviews formed the basis of the patient questionnaire that the National Diabetes Register will begin using soon.

PHOTO: CHARLOTTA SJÖSTEDT

Estimating the future costs of type the case of

The Swedish National Diabetes Register (NDR) has been a crucial source of data for predicting current and future costs of type 2 diabetes.

The richness of NDR data, the many key articles in leading international scientific journals, and the high participation rate of the type 2 diabetes population in Sweden give researchers a unique opportunity to provide decision makers with policy analyses that are rarely possible elsewhere.

Why the focus on the costs of diabetes? For one thing, the increase in prevalence of type 2 diabetes is a global concern. Several reports also point to increasing incidence

accompanied by earlier onset. This shines the spotlight on the costs and burden of the disease from a health policy perspective and is a concern for healthcare planners around the world.

distribution of the costs of the burden of type 2 diabetes depends on the organization of healthcare financing in the particular country or health system: whether it is tax financed or paid for through private health insurance, or out-of-pocket.

The increasing prevalence of diabetes is associated with greater pressure on the healthcare system. But type 2 diabetes is a complex disease such that complications at various stages demand specific healthcare resources. From a health policy perspective, there is an urgent need for forecasts concerning the consequences of current incidence and future prevalence of type 2 diabetes. What does current diabetic prevention mean for future costs? What will the outcome be of current diabetes care, now that UKPDS findings on the long-term benefits of intensive risk factor control have been widely accepted and implemented as the standard of care?

The burden of diabetes

The burden of type 2 diabetes is shared by many people. There is the direct burden on the patient and family due to reduced health. Individuals with type 2 diabetes need more health care: preventive treatment to keep well-known risk factors under control, increased risk of cardiovascular events, including myocardial infarction and stroke; peripheral vascular disease, including amputation; and kidney disease, including end-stage conditions with the need for dialysis or transplant. These health consequences may also have broader implications and impact on productivity, leading to sickness absence and ultimately to early retirement. The



KATARINA STEEN CARLSSON,
Research director, PhD in Economics

2 diabetes:

Sweden

This was not always the case, and a significant percentage of individuals who have type 2 diabetes may not have received the current standard of care from the beginning.

Estimating today's costs of diabetes care is a challenge for the reasons outlined above: it is a complex disease with a multitude of complications; but the patient group is also large and heterogeneous as regards age, duration, current treatment, level of risk factor control, concomitant disease, lifestyle choices, etc. Forecasting future costs is even more challenging. Any estimate of the costs of diabetes relies heavily on the quality of data in terms of their representativeness, the amount and quality of information available about key demographic and clinical factors, and simulation models based on risk equations that suit the relevant healthcare context.

Costs of type 2 diabetes today – what do we know?

A handful of studies based on national or selected patient data have estimated current total societal costs of diabetes or total healthcare costs for diabetes in Sweden. The average annual healthcare costs per person with diabetes

has been estimated at between SEK 36,000 and SEK 49,000 using healthcare register data. These studies do not generally distinguish between costs of diabetes per se and costs of other healthcare consumption unrelated to diabetes.

Estimating the percentage attributable to diabetes is an empirical question. A Swedish study in 2008 showed that while the costs for individuals with diabetes younger than 50 were about quadruple those of people of the same age in the general population, this “diabetes factor” was less than double for people age 65 years and older. The primary reason for the discrepancy was that healthcare costs for people without diabetes increase dramatically with age.

The general consensus of studies on the costs of diabetes in Sweden, as well as international evidence, is that complications are main drivers of the total. Such studies of observed costs inform health policy and the medical community about the current situation. However, from a policy point of view, a more pressing question is what can be done to impact costs in 5, 10 or 20 years? What actions today might change future costs? Little has

been done to predict future total costs of diabetes as the result of alternative treatment implementation strategies.

Predicting costs of type 2 diabetes in 2020 and 2030 – a data-intensive task

New risk equations suitable for health economic simulation models were published in 2013 based on collaboration between Lund University and Swedish National Diabetes Register. These risk equations for a key set of macrovascular diabetic complications confirmed the value of making context-specific estimates of risk equations. It also became obvious that outcomes in diabetes populations differ both among countries and over time.

A study at the Swedish Institute for Health Economics (IHE) has used these new macrovascular risk equations in the validated IHE Cohort Model of Type 2 Diabetes to forecast future costs of diabetes. The model uses Markov health states in order to capture important microvascular and macrovascular complications, as well as premature mortality, due to type 2 diabetes. The figure is a highly simplified illustration of the model. It makes predictions for preventive treatment

costs that are defined by the user, annual risks of diabetic complications and events, as well as their costs, depending on cohort baseline characteristics and disease progression.

Estimating costs of type 2 diabetes in 2020 and 2030 relies heavily on being able to describe the prevalent population accurately. Clinical trial populations are typically subject to selective inclusion and exclusion criteria, making them representative of only part of the intended population. The analyses of costs of type 2 diabetes

in the future used the rich population data from the NDR. We downloaded aggregate group-level statistics for individuals with type 2 diabetes using “Knappen,” the open access database website run by the NDR at www.ndr.nu/#/knappen. The statistics at Knappen provided a baseline description by age, sex, current type of glycemic control treatment, and current blood glucose levels. An additional literature review of the broad NDR publication list supplied further information for baseline characteristics of newly diag-

nosed individuals and those with high risk factor levels. Information was also collated based on detailed annual reports from the NDR.

In order to describe the prevalent diabetes population in 2013, the baseline year, we had a total of 2,592 cohorts (groups), each with their own setup of demographic clinical and risk factor characteristics. In addition, annual incident cohorts were broken down into 72 different group. A technical report of study data, methodology and results is available at www.ihe.se

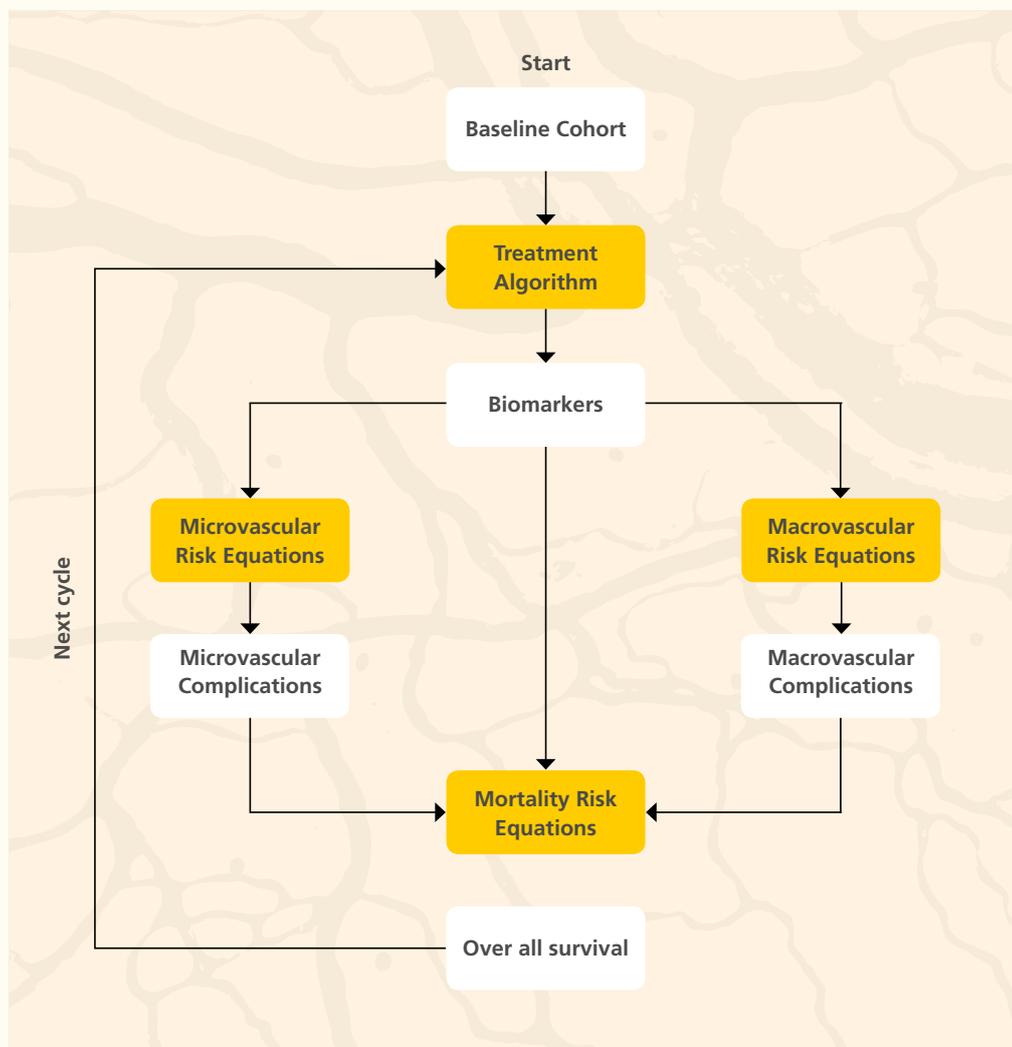


Illustration of the model to make predictions for preventive treatment costs that are defined by the user, annual risks of diabetic complications and events, as well as their costs, depending on cohort baseline characteristics and disease progression.

Will increased preventive efforts reduce costs of type 2 diabetes in the future?

Yes, small changes in line with national recommendations and guidelines may impact the incidence of diabetic complications and premature mortality according to model predictions. Reductions in annual costs of complications will be large enough by 2030 to offset increased costs for preventive measures, which will be administered mostly by primary care in the case of Sweden.

What changes in diabetes treatment were then analyzed? Basically we assumed that patients needed to intensify glucose lowering therapies a little earlier than is typically observed today. A little earlier was defined as threshold values 3-5 mmol/mol lower than today, for instance prescribing metformin at 59 mmol/mol rather than at 62 mmol/mol, at least in cohorts younger than 75. The setup relied on national and international guidelines that recommend individualized treatment-balancing goals and recognize the risk of excessive glycemic control, especially among the elderly. The model also assumed that it would not be possible to intensify treatment earlier without increasing the frequency of primary care appointments and thus costs.

Both earlier treatment and more appointments would increase preventive care costs by about SEK 320 million by 2030 at current price level. That would correspond to 1.5 percent of the total estimated annual costs of diabetes of SEK 21 billion. Meanwhile, costs of diabetic complications would be 1.3 percent lower by 2030, as opposed to not increasing the preventive measures. The lower incidence of complications would also reduce costs of lost production by 0.2 percent. Overall the model predicted cost neutrality of increased preventive efforts in the long run.

New uses of the NDR data

The report of IHE is an example of how data from the NDR, including its online service, can be used to provide decision makers in health care with forecasts based on facts and best available evidence concerning the current diabetes population. Thanks to the resources at NDR, we used data that covered essentially all people with type 2 diabetes.

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Nationwide results for

This section presents nationwide results over time. We have selected a number of indicators – additional results appear on our website. The 20-year report of the NDR evaluates diabetes care in relation to the guidelines of the National Board of Health and Welfare while shedding light on patient populations, treatments, results and processes. The objectives of diabetes treatment should be individualised on the basis of each patient’s circumstances. Instead of a single target level, the following discussion focuses on averages, proportions and several different targets. Particular patient populations are highlighted.

Number of patients and classification of diabetes

The results are presented for specialist clinics broken down by clinical classification of diabetes. All persons with diabetes in primary care are reported as one group. A total of 97% of patients treated at specialist clinics have been clinically classified. A total of 97% of patients in primary care have been classified as type 2 diabetes, while only 3% developed the disease when they were younger than 40 and are receiving insulin treatment.

NDR’s scientific reports define type 1 diabetes as patients with disease onset at age younger than 30 years and have insulin treatment only. Type 2 diabetes, on the other hand, are defined epidemiologically as patients age 40 or older who are receiving 1) dietary treatment or taking tablets only, or 2) insulin treatment, whether or not they are taking tablets. This breakdown has proven to coincide very well with the clinical classification in the NDR. However, a few percent of patients whom the register classifies epidemiologically as type 2 diabetes have latent autoim-

mune diabetes in adults (LADA).

In Sweden almost all patients with type 1 diabetes attend specialist clinics, i.e., outpatient clinics with specialists in diabetology/endocrinology. These clinics also care for patients with complicated type 2 diabetes or many patients with secondary diabetes. Most patients with type 2 diabetes attend primary care, and are seen by general practitioners and diabetes nurses/educators.

The three patient populations are:

- All patients in primary care
- Type 1 diabetics treated at specialist clinics
- Type 2 diabetics treated at specialist clinics

The tables describe the clinical characteristics of the three populations. Persons with type 2 diabetes have a higher average age and shorter disease duration in primary care than at specialist clinics. The fact that specialist clinics are reporting fewer and fewer cases of type 2 diabetes suggests that primary care is assuming increasing

responsibility for this population. As is evident from tables the distributions of age, sex and diabetes duration have been relatively unchanged over the years; thus comparing trends in various risk factors and clinical characteristics is possible without adjustments. Unpublished data shows that adjustment for demographic variables changes the estimates only negligibly.

Participation rate

Population-based data were obtained from the Swedish National Diabetes Register (NDR). The Swedish NDR was initiated in 1996 as a tool for quality assurance in diabetes care. National results are published in yearly reports and the register is administrated from Centre of Registers in Region Vastra Gotaland, Gothenburg, Sweden (www.NDR.nu). Reporting to the register is not mandatory, but all specialist clinics and primary healthcare centres are encouraged to do so. In 2015 the register received reports from all counties, all 90 specialist clinics and 1,268 primary care clinics. Hence, 100% of specialist clinics and 95% of primary health care

1996–2015

centres participate. In Sweden almost all patients with type 1 diabetes receive their treatment at specialist clinics.

Annual reporting to the NDR is carried out by trained physicians and nurses via the Internet or by automatic transmission of data from medical records. Information is collected during patient visits at specialist clinics and primary health care centres nationwide. All included patients have agreed by informed consent (verbal or written) to register before inclusion.

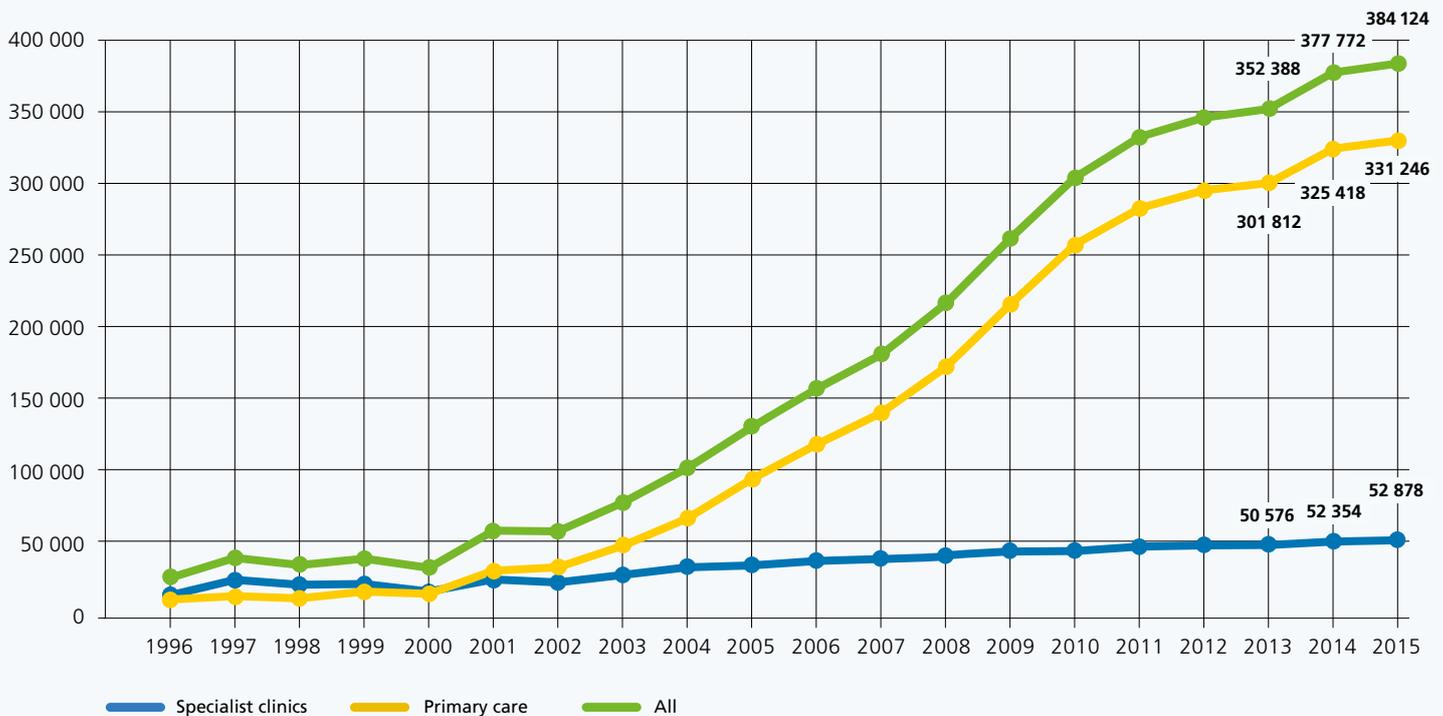
Approximately 4% of Swedes have

diabetes, though the prevalence varies from one county to another. Type 2 diabetes represents approximately 90% of all cases. On average men are younger when they develop the disease than women. The figure shows the number of patients who were reported between 1996 and 2015, broken down by primary care and specialist clinics. Although the number of reported appointments has levelled off in recent years, we still note an increase in the number of reports. More than 380,000 appointments

were reported to the NDR in 2015, representing approximately 90% of adult patients with diabetes in Sweden. The ascertainment level is equal for type 1 and type 2 diabetes.¹ In 2015 the NDR had included 643,431 individuals since 1996.

The nationwide coverage and prospective nature of the register allows for assessment of clinical and health care related investigations, with representative and real world data.

Number of patients entered in NDR, 1996–2015



Patients with diabetes in primary care.

Year	Number years (SD)	Mean age, years (SD)	Mean duration	Men (%)
1996	10 949	68,8 (12,1)	9,3 (8,1)	5 678 (51,9)
1997	10 730	67,9 (13,2)	9,9 (8,8)	5 527 (51,5)
1998	11 922	68,8 (12,2)	9,4 (8,1)	6 136 (51,5)
1999	14 149	69,0 (12,0)	9,1 (7,9)	7 524 (53,2)
2000	17 665	69,0 (12,3)	9,1 (8,3)	9 195 (52,1)
2001	26 090	68,5 (12,3)	8,8 (8,2)	13 608 (52,2)
2002	38 388	68,4 (12,1)	9,0 (8,4)	20 438 (53,2)
2003	50 472	68,0 (12,0)	8,7 (8,2)	27 216 (53,9)
2004	69 650	68,0 (11,8)	8,4 (7,8)	37 561 (53,9)
2005	97 528	68,0 (12,0)	8,5 (7,8)	52 369 (53,7)
2006	119 988	68,0 (11,8)	8,5 (7,7)	65 228 (54,4)
2007	144 103	67,8 (11,8)	8,6 (7,7)	79 252 (55,0)
2008	180 992	67,8 (11,8)	8,6 (7,8)	99 852 (55,2)
2009	219 606	67,8 (11,9)	8,8 (10)	121 638 (55,4)
2010	259 610	67,9 (12,1)	8,8 (9,8)	143 969 (55,5)
2011	285 896	68,0 (12,1)	9,0 (10,6)	159 525 (55,8)
2012	297 012	68,1 (12,1)	9,2 (9,1)	166 932 (56,2)
2013	307 267	68,2 (12,0)	9,4 (8,2)	174 209 (56,7)
2014	323 074	68,4 (11,9)	9,6 (8,9)	184 138 (57,0)
2015	290 101	68,5 (11,9)	10,0 (8,9)	166 204 (57,3)

Source: NDR – Swedish National Diabetes Register

Patients with type 1 diabetes at specialist clinics.

Year	Number years (SD)	Mean age, years (SD)	Mean duration	Men (%)
1996	5 255	42,1 (13,2)	20,2 (12,3)	2 905 (55,3)
1997	6 884	41,6 (13,3)	20,1 (12,5)	3 770 (54,8)
1998	6 830	42,0 (13,3)	20,1 (12,7)	3 731 (54,6)
1999	8 459	42,9 (13,4)	21,1 (12,9)	4 660 (55,1)
2000	9 045	43,4 (13,6)	21,2 (13,0)	5 056 (55,9)
2001	11 924	43,9 (13,9)	21,4 (13,3)	6 631 (55,6)
2002	13 386	44,5 (14,2)	21,7 (13,4)	7 490 (56,0)
2003	16 835	44,8 (14,5)	22,0 (13,8)	9 329 (55,4)
2004	20 705	45,2 (14,6)	22,2 (13,9)	11 543 (55,7)
2005	23 464	45,7 (14,9)	22,7 (14,2)	13 005 (55,4)
2006	25 025	45,9 (15,1)	22,9 (14,4)	13 849 (55,3)
2007	26 897	46,0 (15,3)	23,0 (14,5)	14 945 (55,6)
2008	29 197	45,9 (15,5)	23,0 (14,5)	16 235 (55,6)
2009	29 551	45,9 (15,8)	23,1 (14,7)	16 391 (55,5)
2010	30 089	45,9 (16,1)	23,2 (15,5)	16 714 (55,5)
2011	33 537	45,7 (16,3)	23,2 (14,9)	18 844 (56,2)
2012	35 001	45,7 (16,5)	23,2 (15,0)	19 603 (56,0)
2013	36 460	45,8 (16,7)	23,5 (15,7)	20 370 (55,9)
2014	38 732	46,1 (16,8)	23,7 (15,8)	21 593 (55,7)
2015	33 927	46,5 (17,0)	24,2 (16,0)	18 734 (55,2)

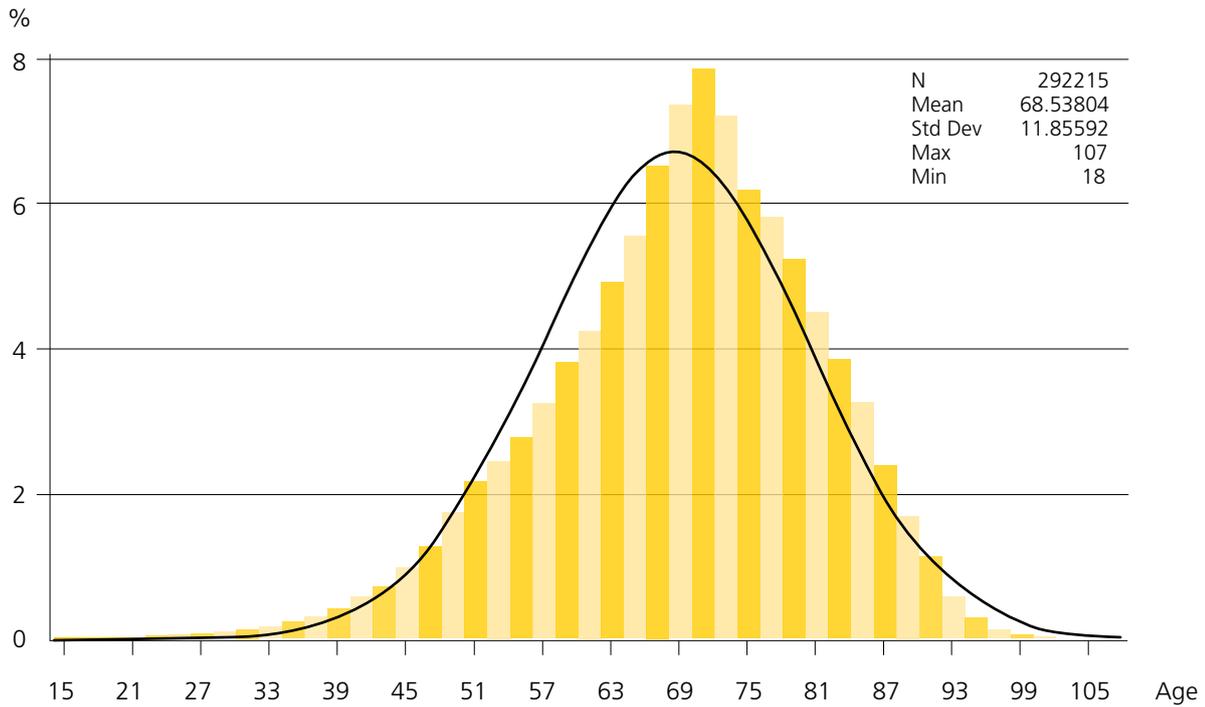
Source: NDR – Swedish National Diabetes Register

Patients with type 2 diabetes at specialist clinics.

Year	Number years (SD)	Mean age, years (SD)	Mean duration	Men (%)
1996	2 259	57,1 (11,4)	11,2 (8,5)	1 358 (60,1)
1997	2 826	57,7 (11,2)	11,4 (8,2)	1 718 (60,8)
1998	2 731	57,4 (11,2)	11,7 (8,5)	1 605 (58,8)
1999	3 803	58,2 (11,4)	11,7 (8,6)	2 318 (61,0)
2000	4 143	58,7 (11,2)	12,1 (8,9)	2 547 (61,5)
2001	5 564	59,0 (11,8)	12,1 (9,0)	3 486 (62,7)
2002	6 480	59,7 (11,8)	12,2 (9,0)	4 086 (63,1)
2003	8 111	60,2 (12,1)	12,6 (9,1)	5 130 (63,2)
2004	10 309	60,7 (12,2)	12,8 (9,2)	6 541 (63,4)
2005	11 625	61,5 (12,4)	13,1 (9,4)	7 389 (63,6)
2006	12 390	62,0 (12,3)	13,1 (9,2)	7 951 (64,2)
2007	12 233	62,3 (12,4)	13,7 (9,5)	7 832 (64,0)
2008	12 336	62,3 (12,6)	13,9 (9,6)	7 869 (63,8)
2009	12 799	62,6 (12,4)	13,8 (9,6)	8 242 (64,4)
2010	12 340	62,8 (12,4)	14,0 (9,7)	8 025 (65,0)
2011	12 259	62,8 (12,5)	14,3 (9,8)	7 903 (64,5)
2012	11 048	62,8 (12,5)	15,0 (9,9)	7 193 (65,1)
2013	10 258	62,7 (12,7)	15,1 (9,9)	6 599 (64,3)
2014	9 931	63,1 (12,7)	15,6 (9,9)	6 377 (64,2)
2015	8 335	63,4 (12,9)	16,3 (9,9)	5 388 (64,6)

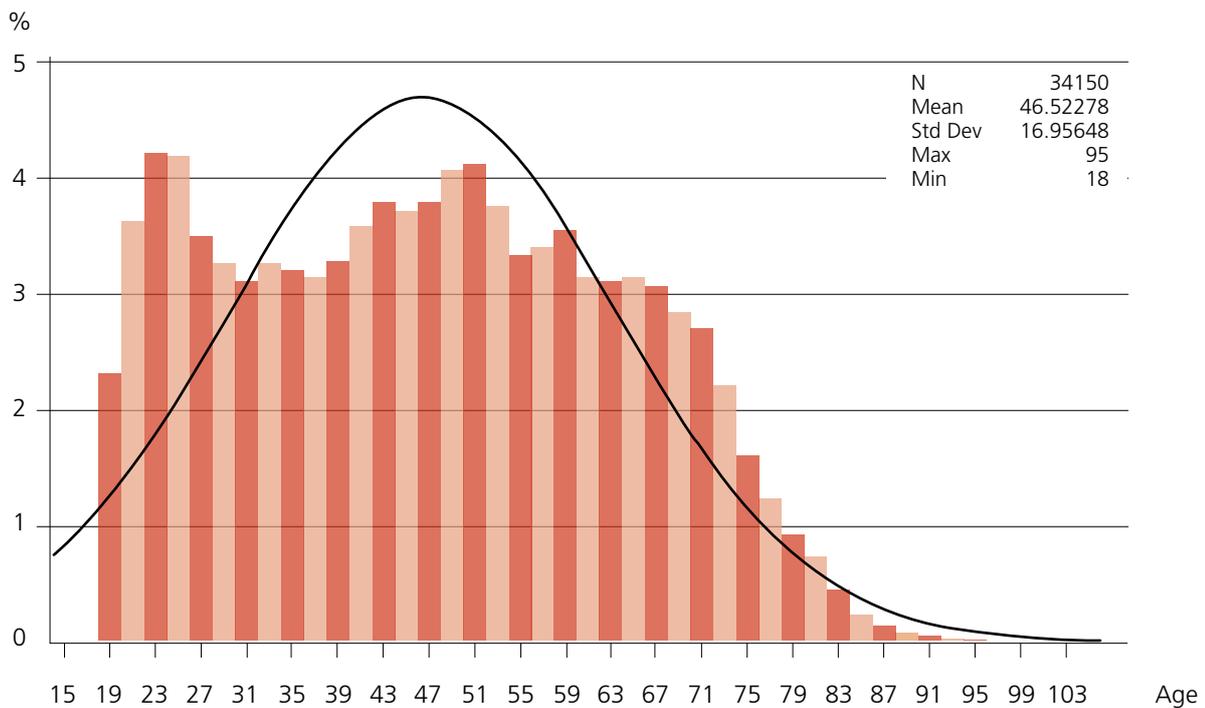
Source: NDR – Swedish National Diabetes Register

Histogram by age. Patients with diabetes in primary care, year 2015.



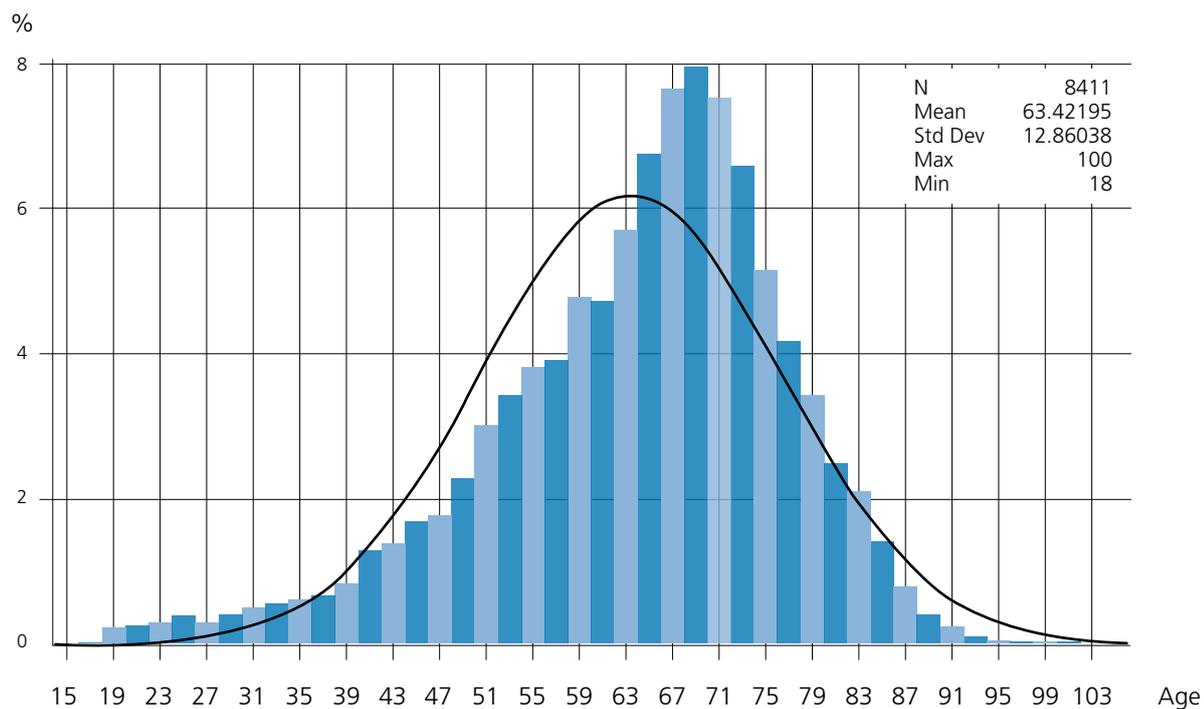
Source: NDR – Swedish National Diabetes Register

Histogram by age. Patients with type 1 diabetes at specialist clinics, year 2015.



Source: NDR – Swedish National Diabetes Register

Histogram by age. Patients with typ 2 diabetes at specialist clinics.



Source: NDR – Swedish National Diabetes Register

Lifestyle

Obesity and overweight is not only a major risk factor for type 2 diabetes, they are also independent risk factors of cardiovascular disease and premature death. Obesity remain a major challenge for individuals with type 2 diabetes.

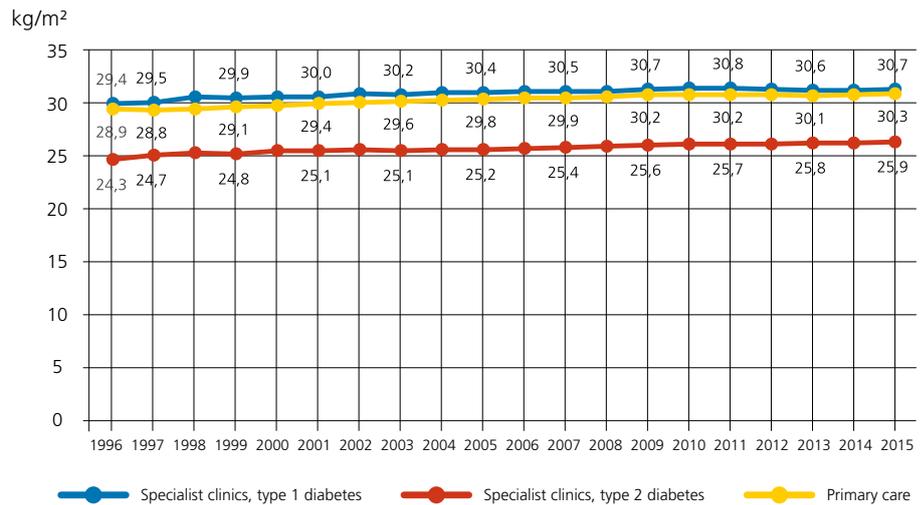
The chapter presents the changes in BMI over 20 years, and trends in proportion of the population with obesity, trends in physical leisure activities over nine years and trends in proportion of smokers.

As is evident from these figures, BMI has increased slightly over the year; proportion of patients that are physically inactive have remained relatively unchanged over the years; smoking rates has increased among persons with type 2 diabetes but declined among those with type 1 diabetes.

Patients with type 2 diabetes who are relatively young

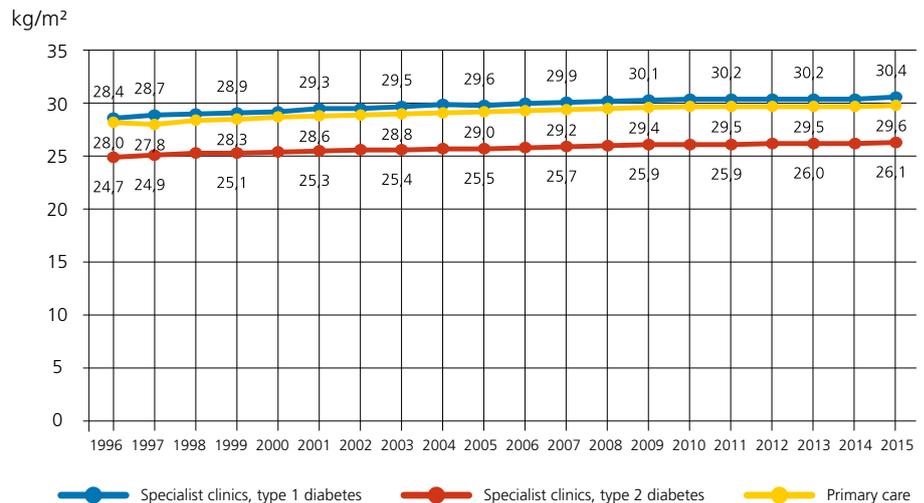
More than one in five 30–60 year-olds smoke and one in four are physically inactive. A total of 54.1% of men and 60.9% of women have BMI ≥ 30 kg/m².

Mean BMI: Women



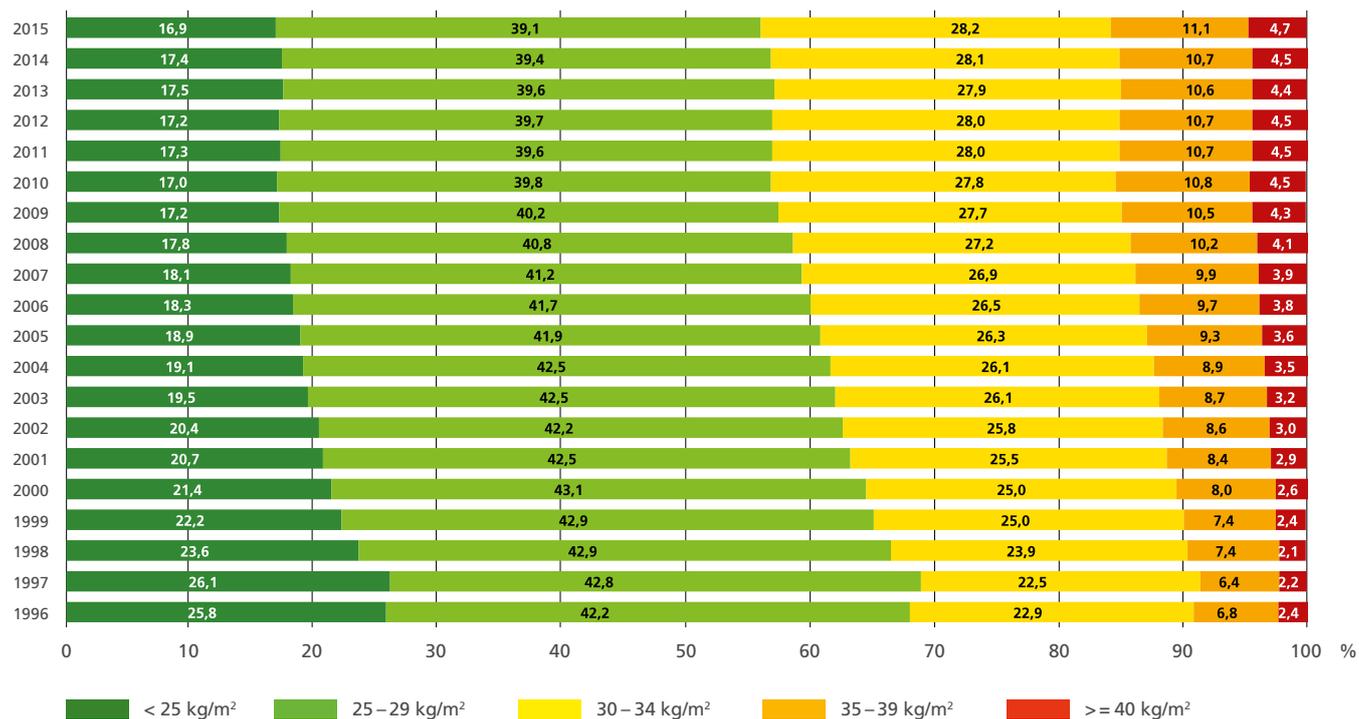
Source: NDR – Swedish National Diabetes Register

Mean BMI: Men



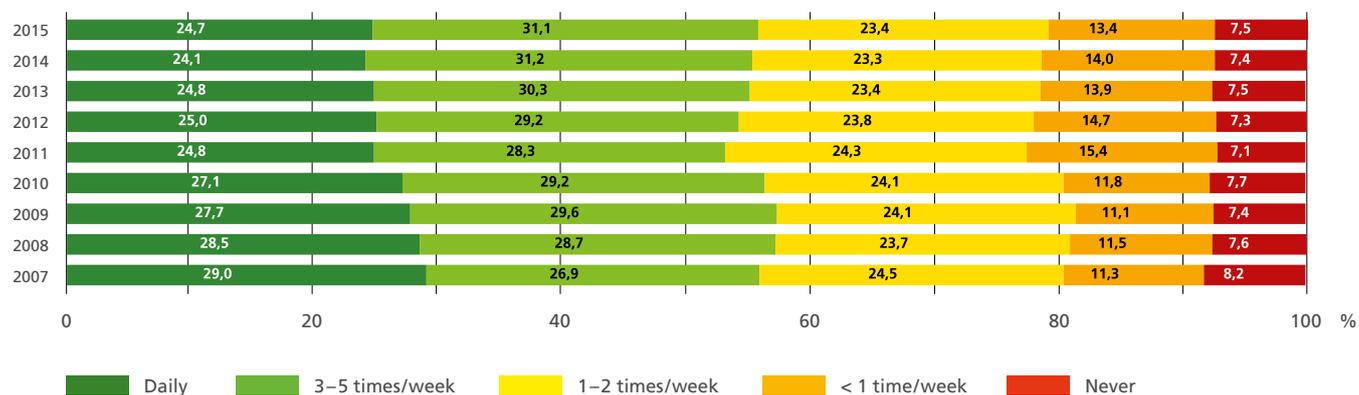
Source: NDR – Swedish National Diabetes Register

BMI intervals: Patients with diabetes in primary care.



Source: NDR – Swedish National Diabetes Register

Physical leisure activities: Patients with typ 1 diabetes at specialist clinics.

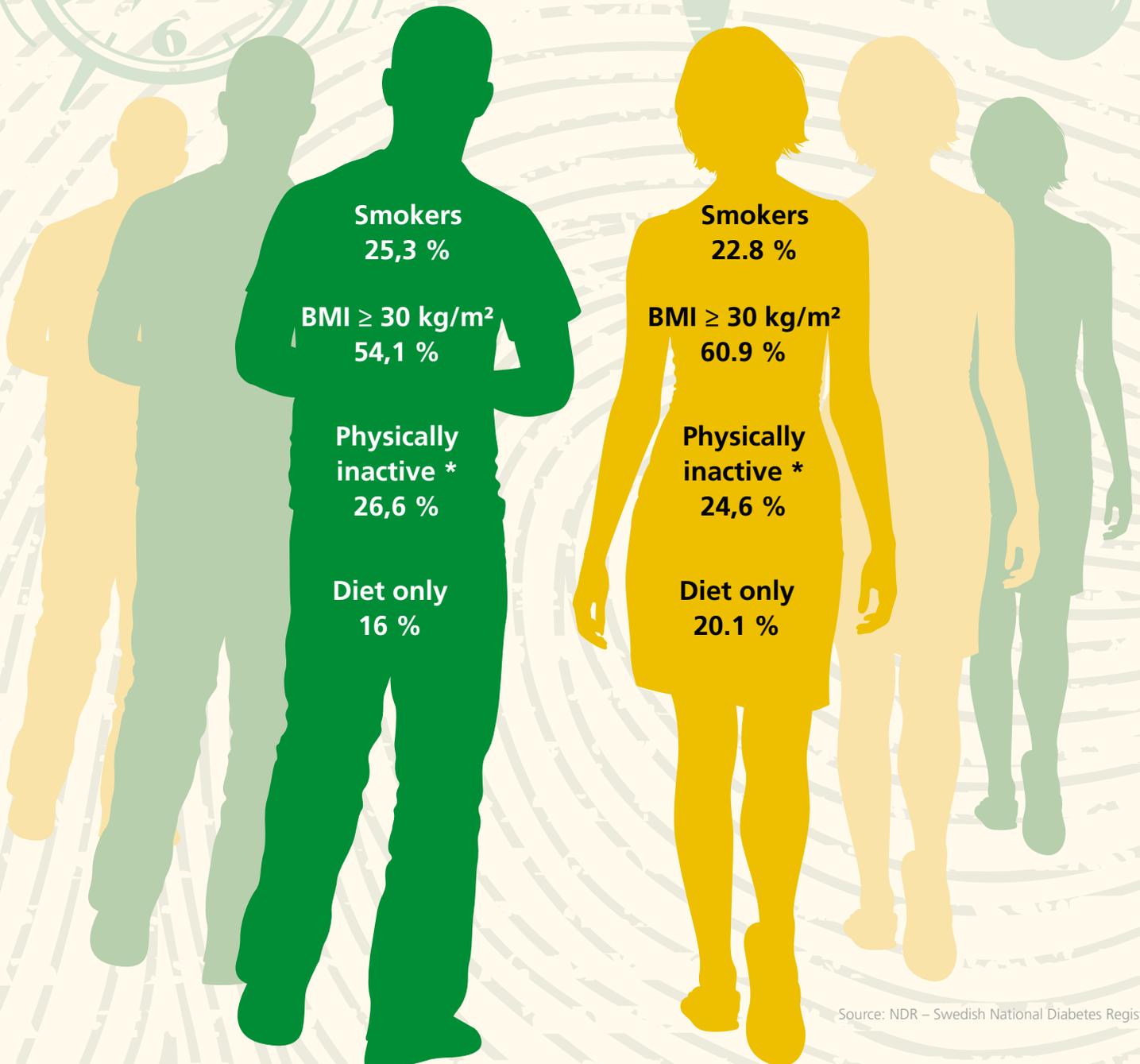


Source: NDR – Swedish National Diabetes Register

Patients age 30–60 in primary care, 2015

Number of men: 41 375

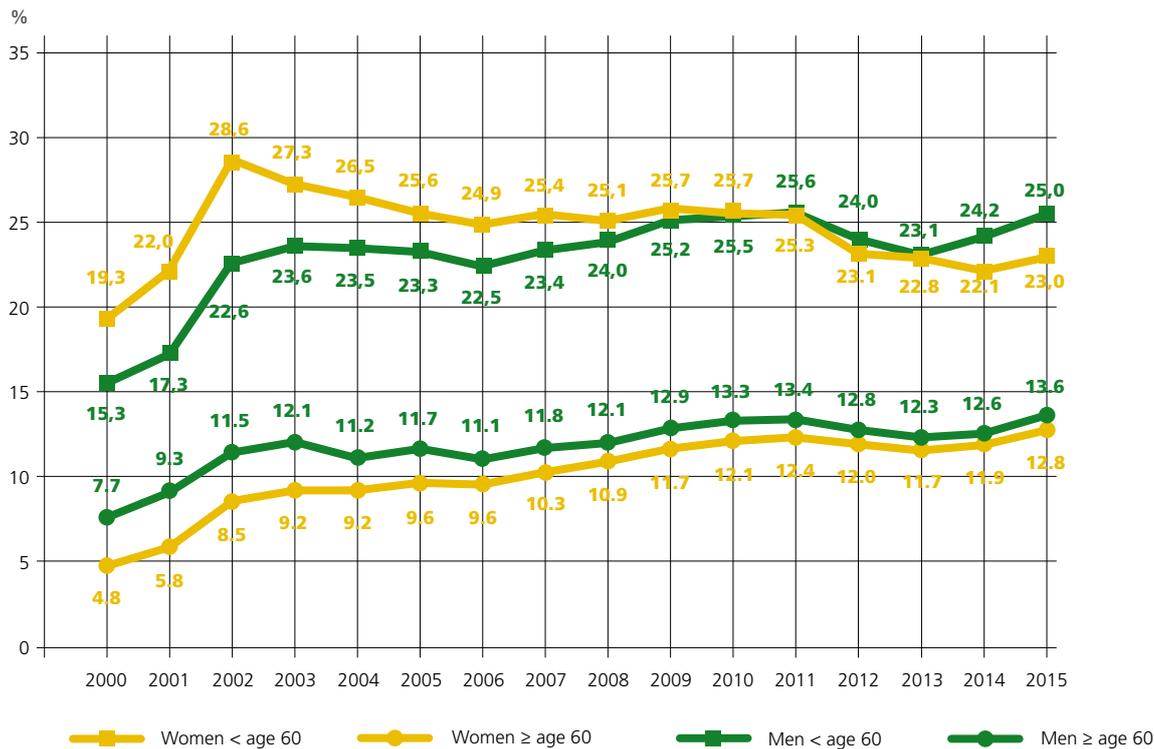
Number of women: 25 999



Source: NDR – Swedish National Diabetes Register

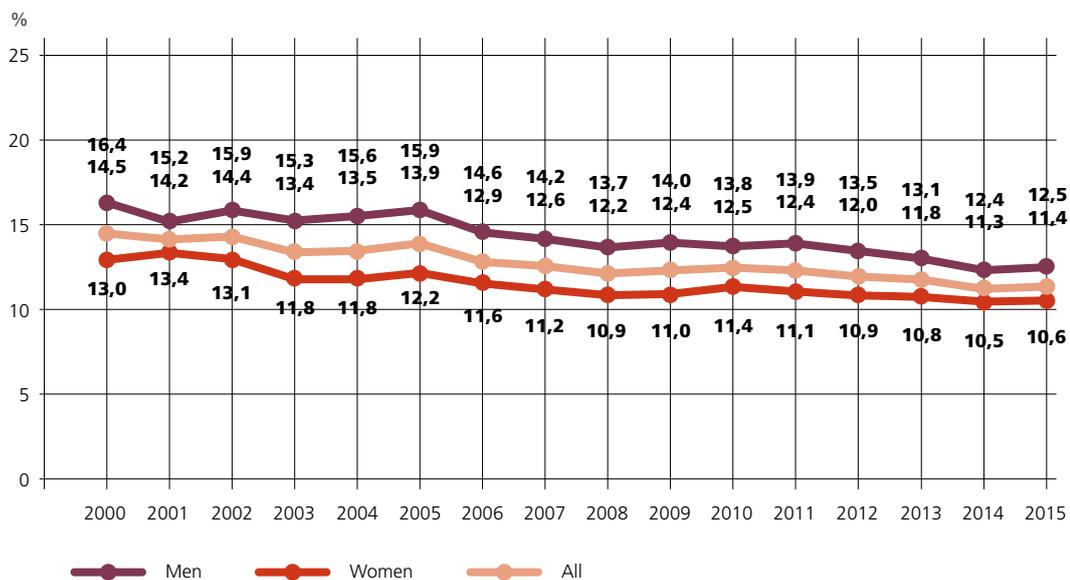
* Physical leisure activity, < 1 time/week

Women and men in primary care who smoke.



Source: NDR – Swedish National Diabetes Register

Type 1 diabetes patients at specialist clinic who smoke



Source: NDR – Swedish National Diabetes Register

HbA1c

HbA1c levels reflect long-term glycaemic control and are strongly correlated with the risk of developing complications of diabetes. Mean HbA1c in 1996 was 68,5, 67,5, 61,4 for persons with type 1 diabetes, type 2 diabetes in specialist clinics and patients in primary care, respectively. HbA1c declined steadily until the year 2007, thereafter it started to increase. The increase abated in 2012 and there has been a decline in the final years.

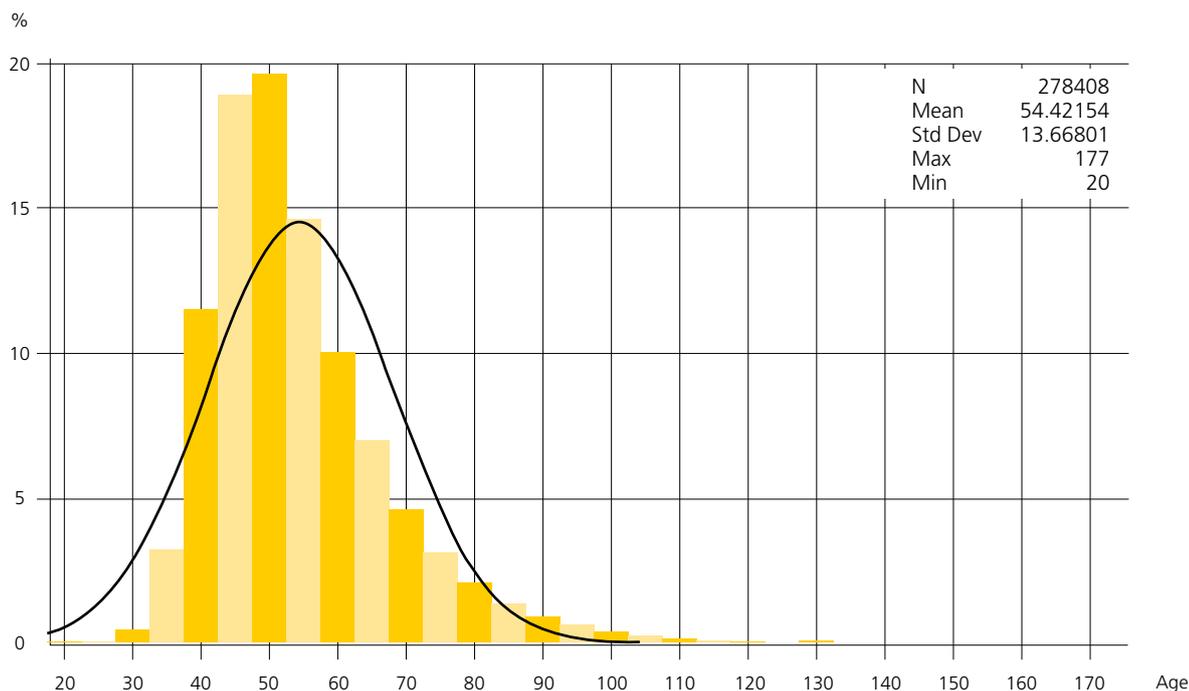
Despite the trends regarding mean HbA1c, a reduction has been noted regarding the proportion of patients having high HbA1c (defined as 70

mmol/mol or above). While the goal is that as many patients as possible remain below 52 mmol/l, individualised treatment is essential and ensuring that as many as possible are at 70 mmol/l or below is equally important. Many projects throughout the country have focused on eliminating high levels through treatment and education; results have been encouraging.

However, much work remains to be done. The national target is to have more than 80% of patients with type 1 diabetes below 70 mmol/mol and more than 90% of patients with type 2 diabetes below 70 mmol/mol.

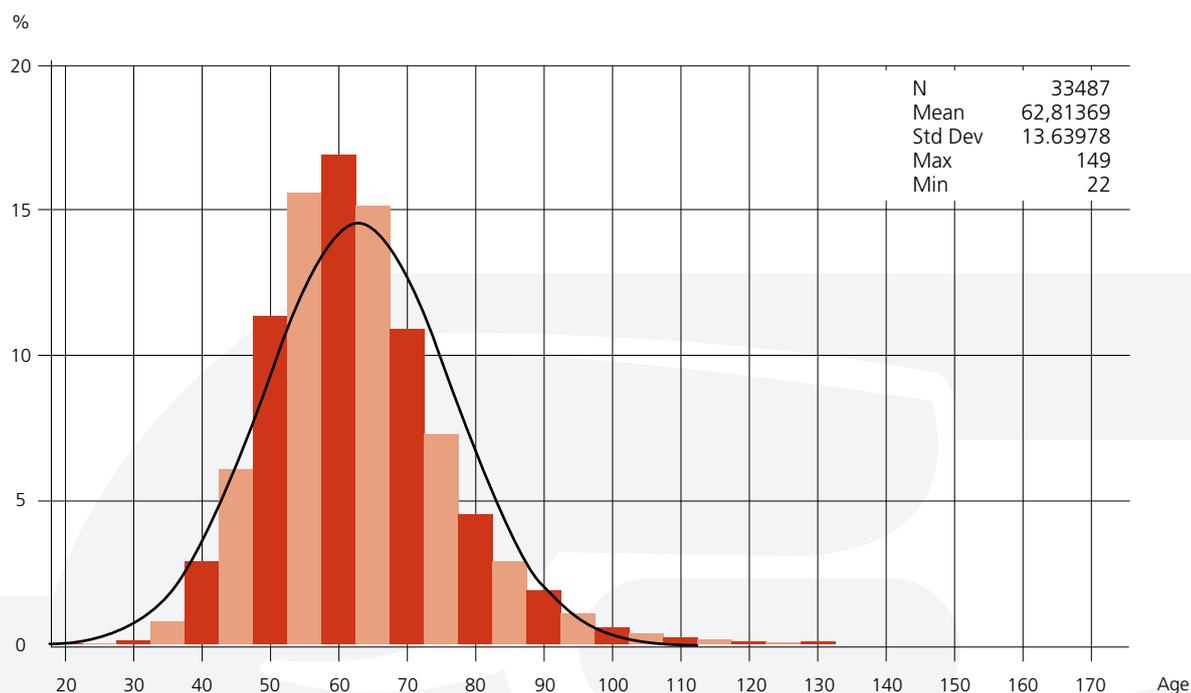
Note that the figures presented in the graphs are unadjusted, but unpublished adjusted data shows virtually identical figures (as explained previously).

Histogram for HbA1c (mmol/mol). Patients with diabetes in primary care, year 2015.



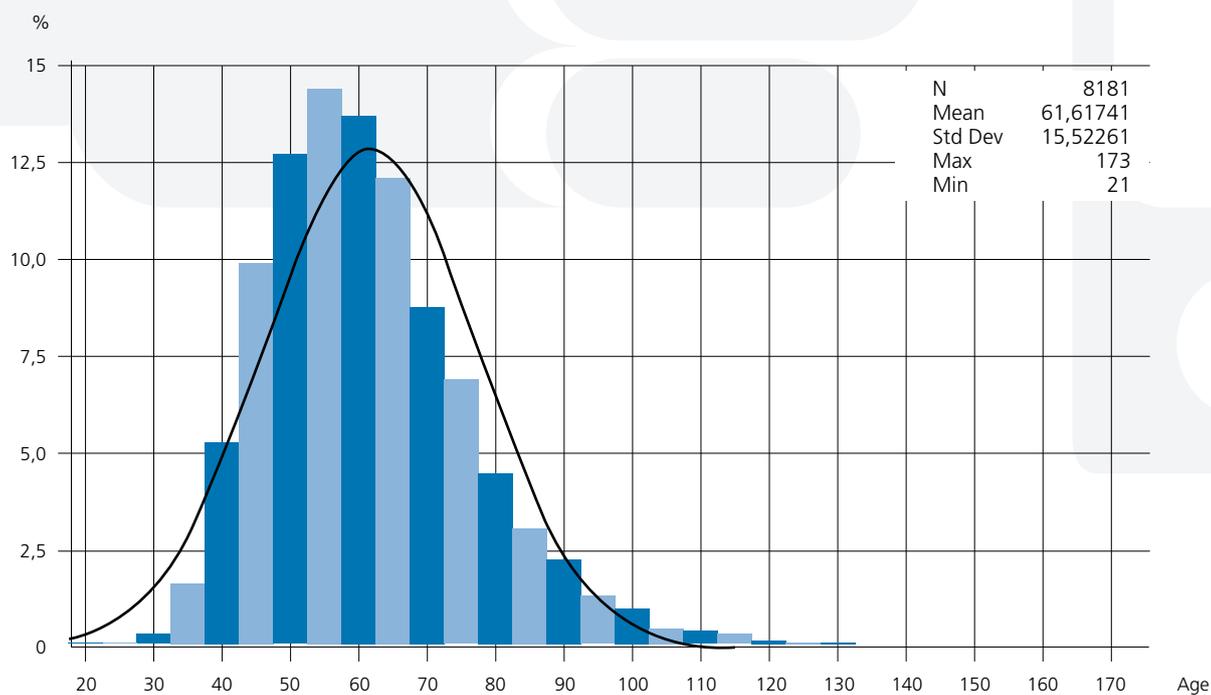
Source: NDR – Swedish National Diabetes Register

Histogram for HbA1c (mmol/mol). Patients with type 1 diabetes at specialist clinics, year 2015.

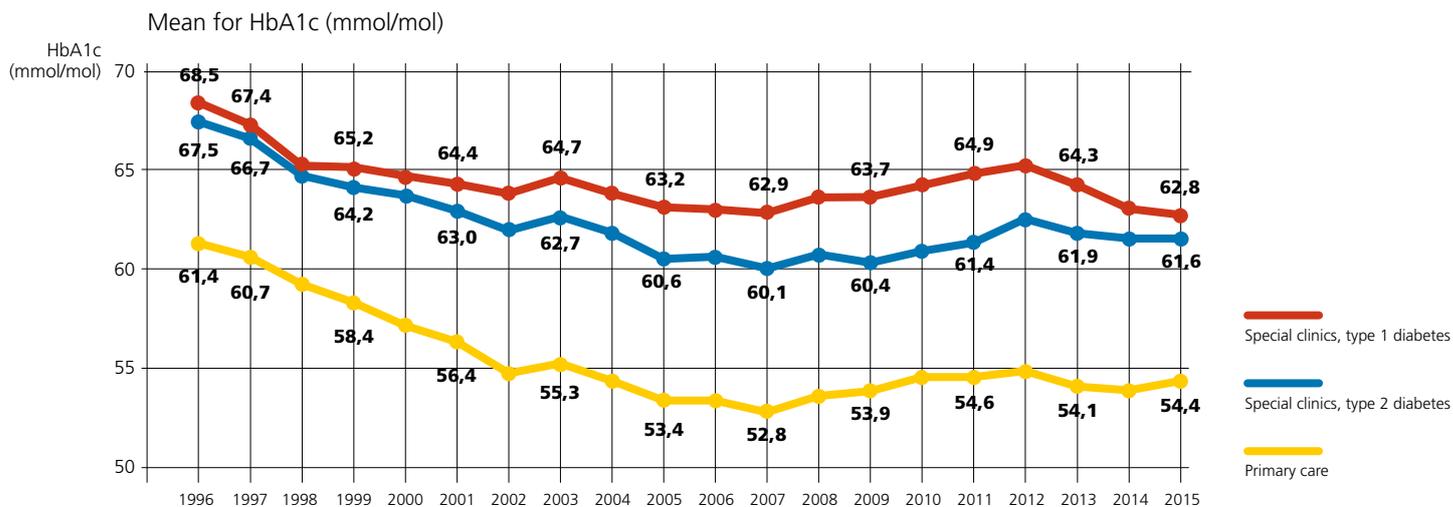


Source: NDR – Swedish National Diabetes Register

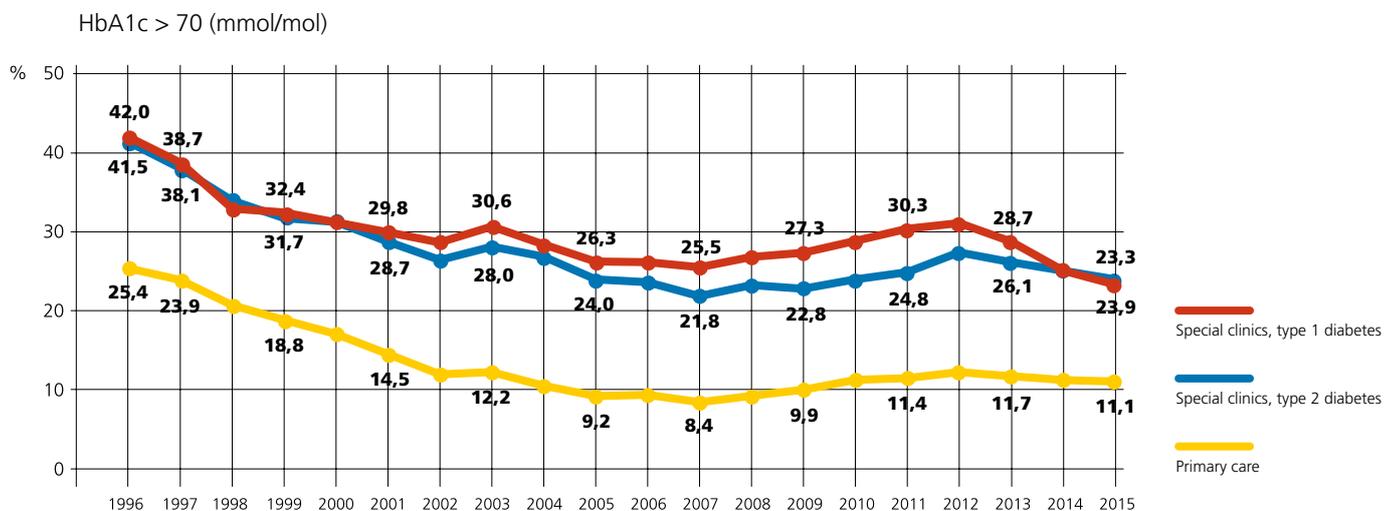
Histogram for HbA1c (mmol/mol). Patients with type 2 diabetes at specialist clinics, year 2015.



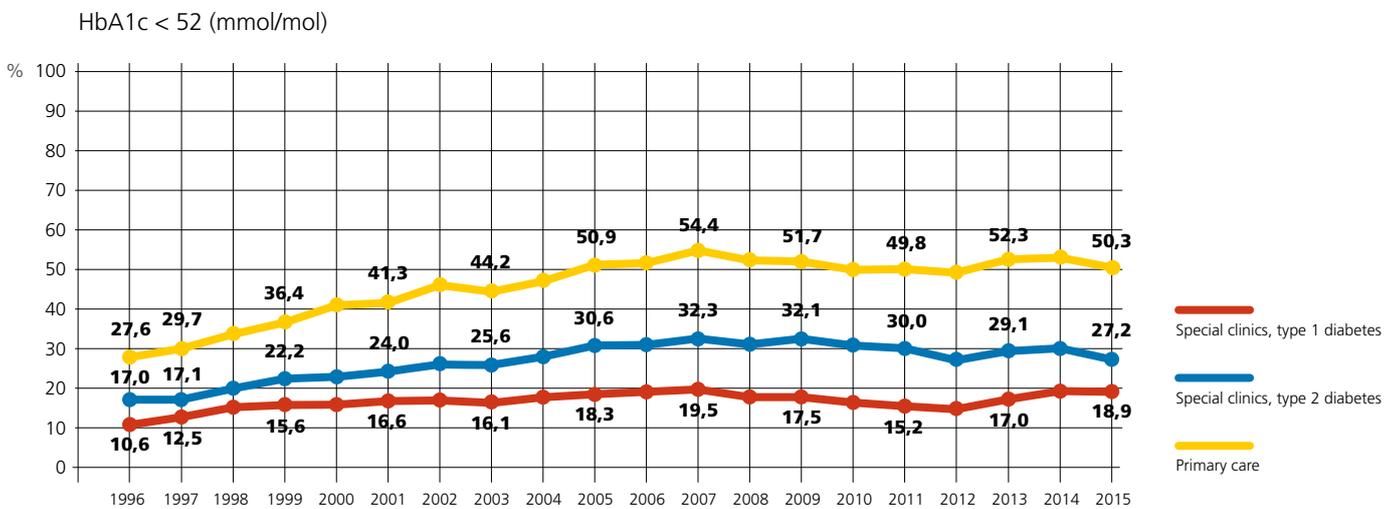
Source: NDR – Swedish National Diabetes Register



Source: NDR – Swedish National Diabetes Register



Source: NDR – Swedish National Diabetes Register



Source: NDR – Swedish National Diabetes Register

Diabetes treatment

This chapter presents various glucose-lowering treatment in different patient categories and over time. As is clear from figure on page 37, the proportion of patients with diabetes in primary care who receive dietary treatment only is declining but still around 20%.

Specialist clinics report that more than 13% of patients with type 2 diabetes are treated with GLP-1 receptor agonists. The use of these agents has increased markedly in specialist clinics. Treatment with only insulin has declined clearly in the same setting, whereas treatment with insulin and oral glucose-lowering agents appears to have declined slightly. Patients

treated only with oral glucose-lowering agents have remained relatively unchanged.

Primary health care clinics have increased their use of oral glucose-lowering agents and reduced treatment with only diet as well as only insulin. The combination of insulin and oral glucose-lowering agents has also increased, but treatment with GLP-1 receptor agonists remain low.

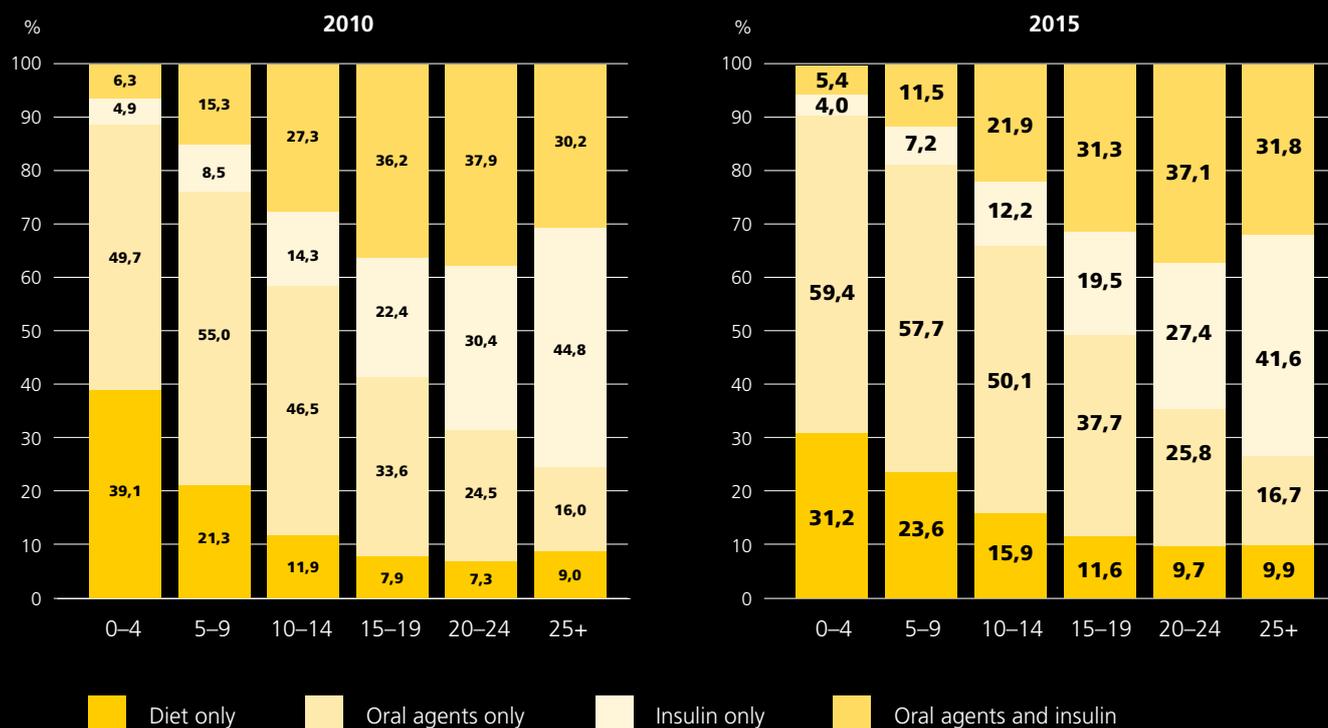
Overall treatment with only diet or only insulin has declined over time, in favour of pharmacologic and combination therapy.

For patients with type 1 diabetes we note a doubling in the use of continu-

ous subcutaneous glucose infusion. Roughly one in 4 patients delivery insulin by means of CSII, which is an encouraging trend given the benefits of CSII.

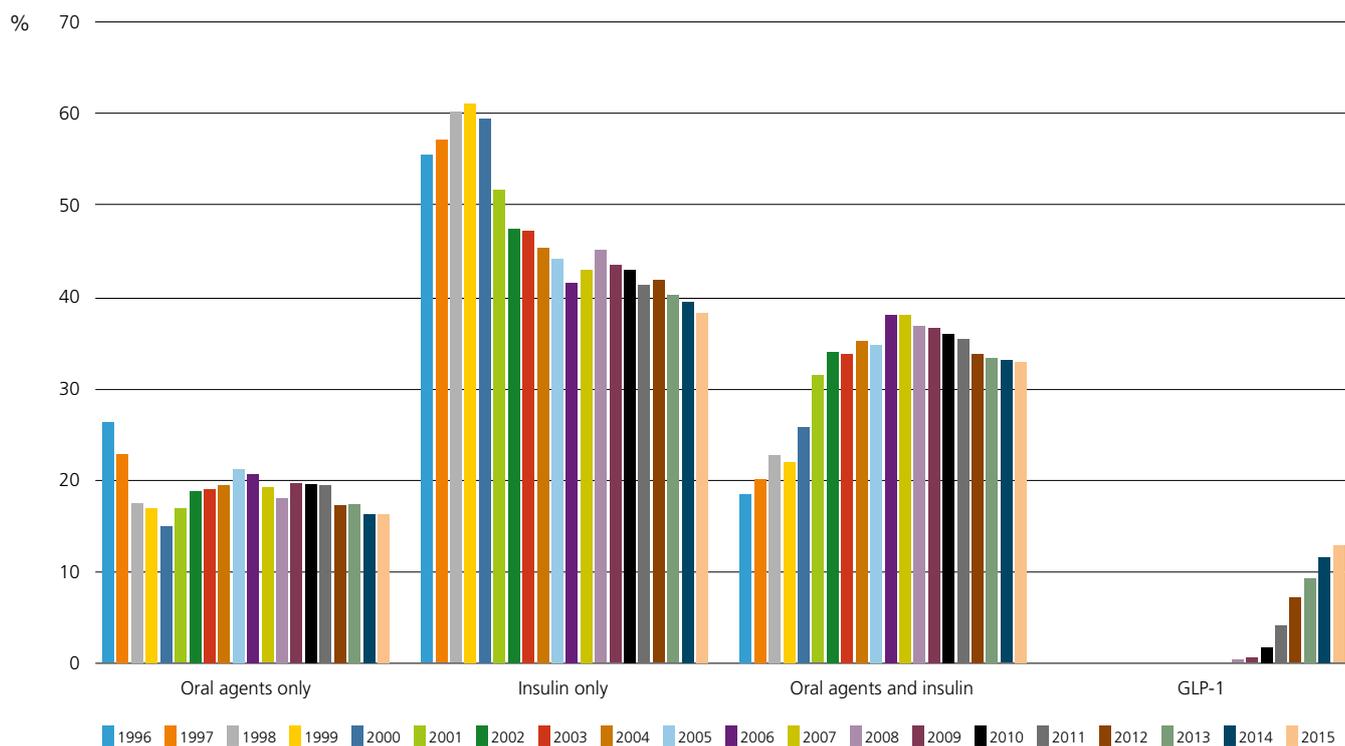
(Insulin pump therapy, multiple daily injections, and cardiovascular mortality in 18,168 people with type 1 diabetes: observational study. *BMJ*. 2015 Jun 22;350).

Various types of glucose-lowering treatment by intervals of diabetes duration. Primary care, 2010 and 2015.



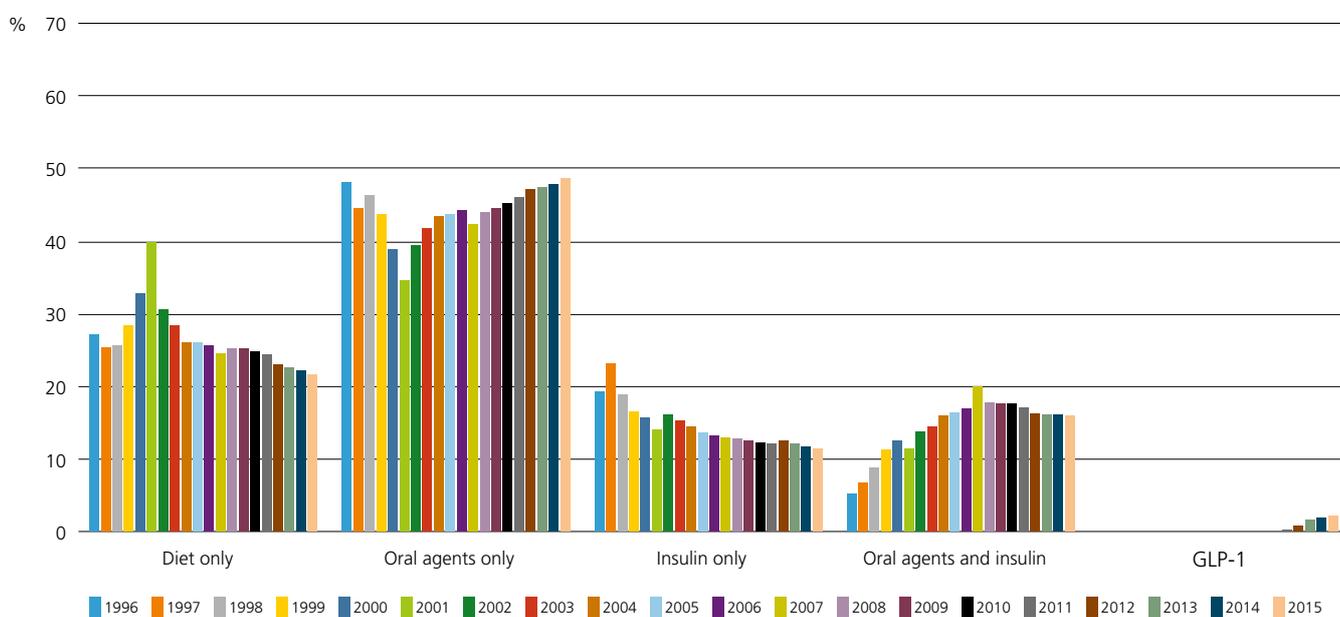
Source: NDR – Swedish National Diabetes Register

Various types of glucose-lowering treatment among patients with type 2 diabetes at specialist clinics.



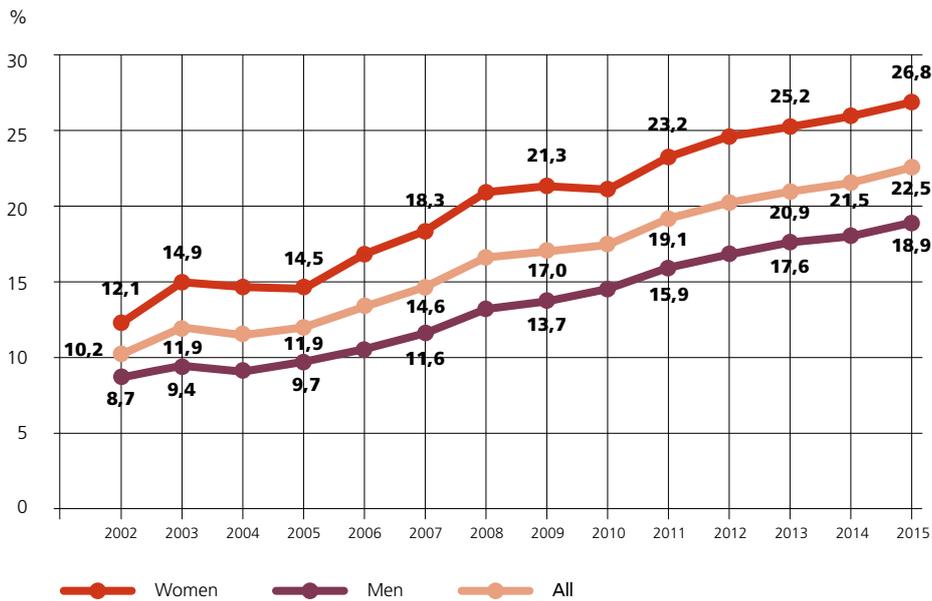
Source: NDR – Swedish National Diabetes Register

Various types of glucose-lowering treatment among patients in primary care.



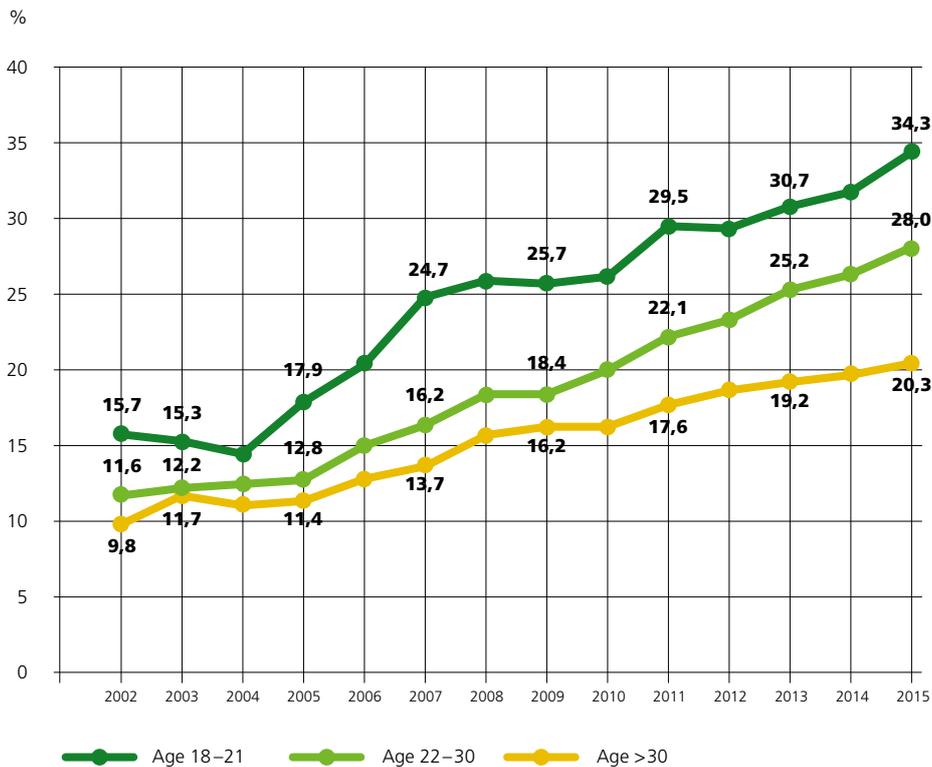
Source: NDR – Swedish National Diabetes Register

Insulin pump among patients with type 1 diabetes at specialist clinics.



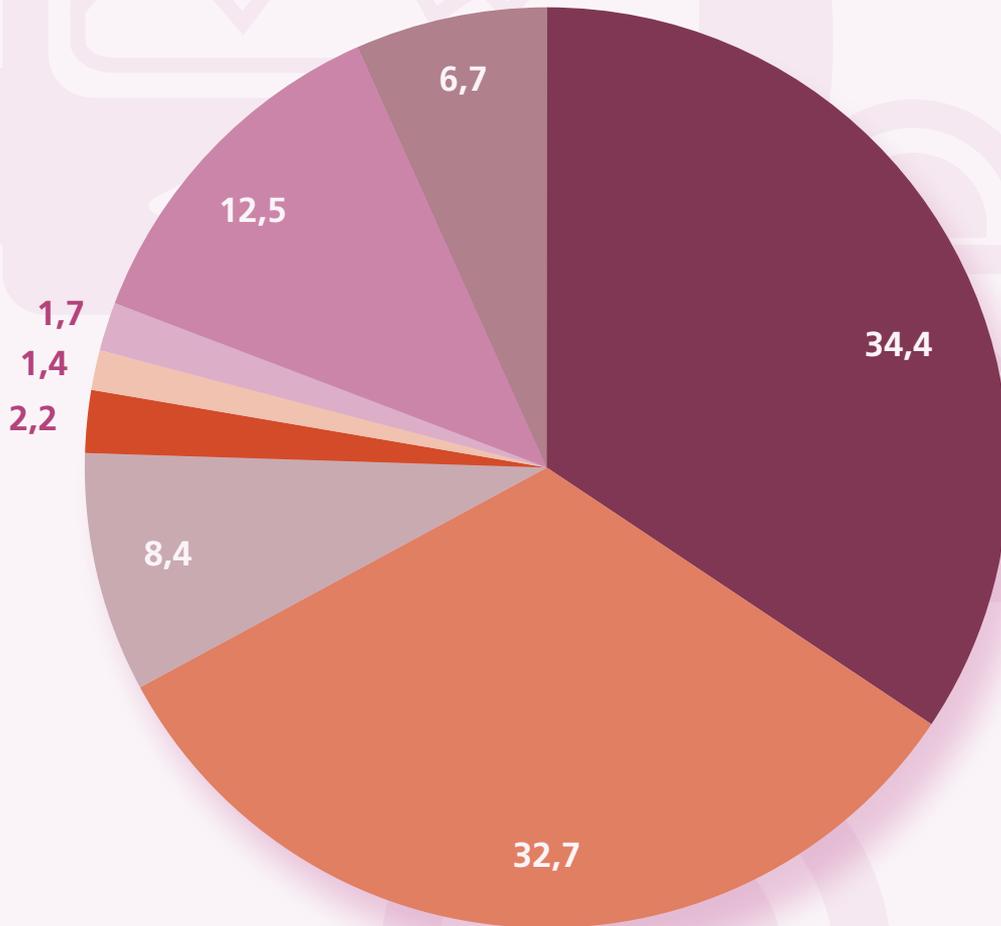
Source: NDR – Swedish National Diabetes Register

Insulin pump among patients in various age groups with type 1 diabetes at specialist clinics.



Source: NDR – Swedish National Diabetes Register

Indication for treatment with continuous subcutaneous insulin infusion (CSII) among patients with type 1 diabetes at specialist clinics.



- Glucose variability
- High HbA1c
- Frequent hypoglycaemias
- Physical activity
- Dawn phenomenon
- Unawareness
- Patients preference
- Facilitation of glycemic treatment

Source: NDR – Swedish National Diabetes Register

Blood pressure

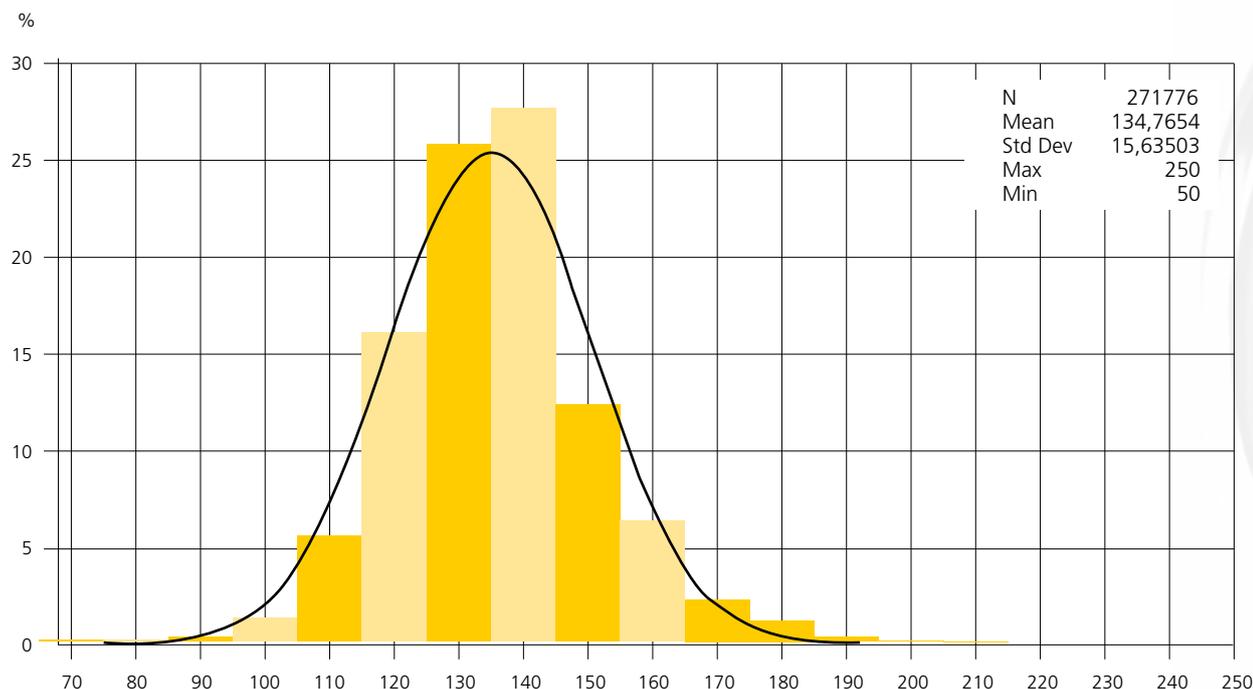
Hypertension significantly increases the risk of kidney failure, cardiovascular disease and other complications among patients with both type 1 and type 2 diabetes. During 1996 and 2012 systolic and diastolic blood pressure declined markedly among all patients with diabetes (Page 42). The decline could be explained by more aggressive use of antihypertensive medications (Page 42). However, there was a slight increase in blood pressure in the final years, in specialist clinics, an observa-

tion that needs to be monitored closely henceforth.

Despite the encouraging trends a great deal remains to be done. The Swedish National Board of Health and Welfare has stated that 90% of patients with type 1 diabetes and 65% of patients with type 2 diabetes should achieve a blood pressure below 140/85 mmHg. Only 75% of patients with type 1 diabetes and 54% of patients with type 2 diabetes have achieved the target.

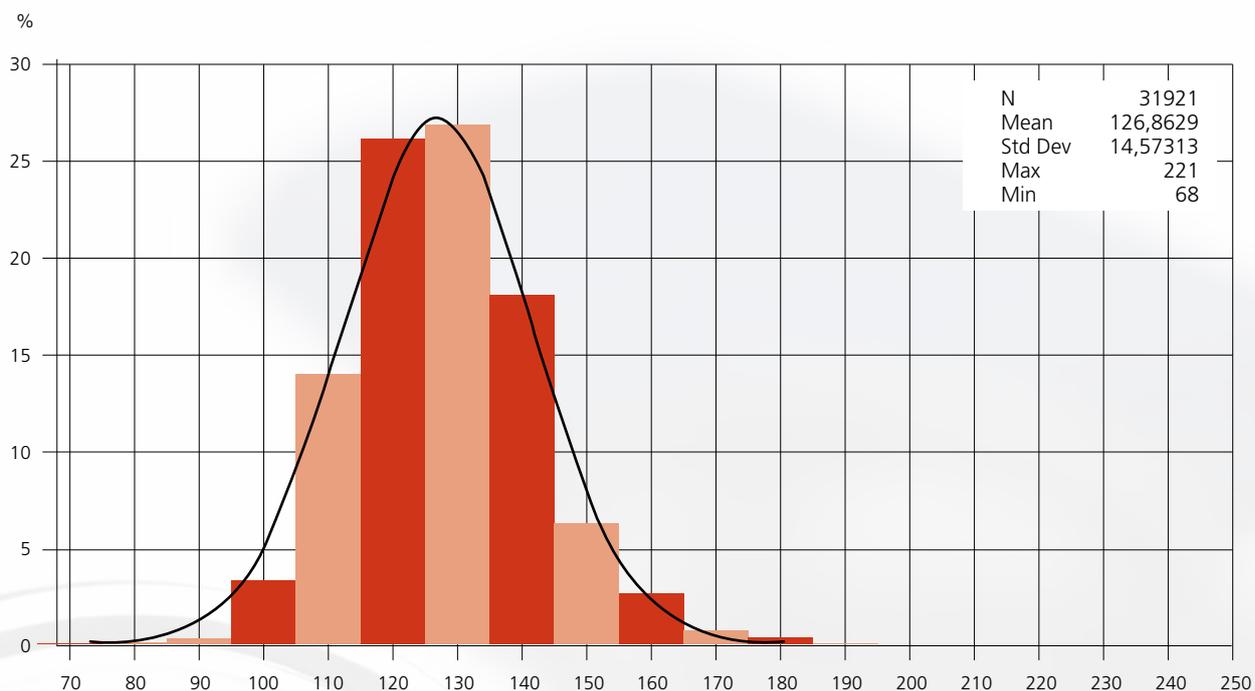
Ongoing research projects at the NDR are attempting to evaluate whether the favourable blood pressure trend is – as would be expected – reducing long-term risk of developing cardiovascular disease.

Histogram for systolic blood pressure (mm Hg). Patients with diabetes in primary care, year 2015.



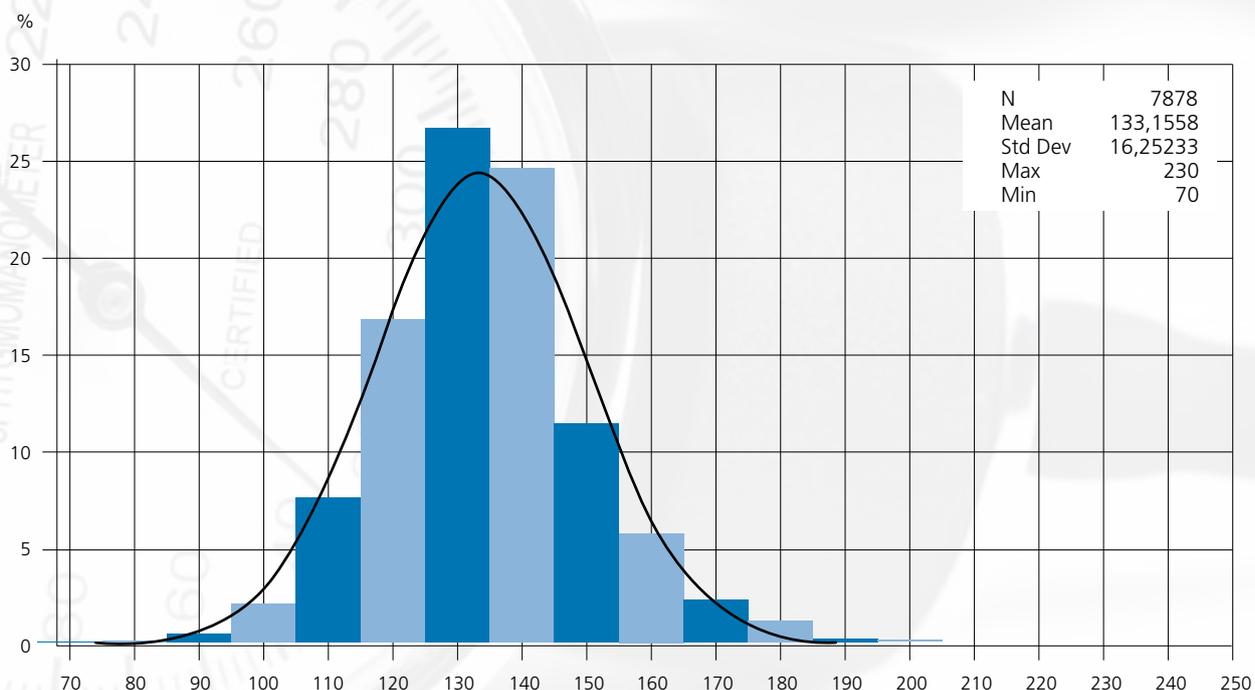
Source: NDR – Swedish National Diabetes Register

Histogram for systolic blood pressure (mm Hg). Patients with type 1 diabetes at specialist clinics., year 2015.



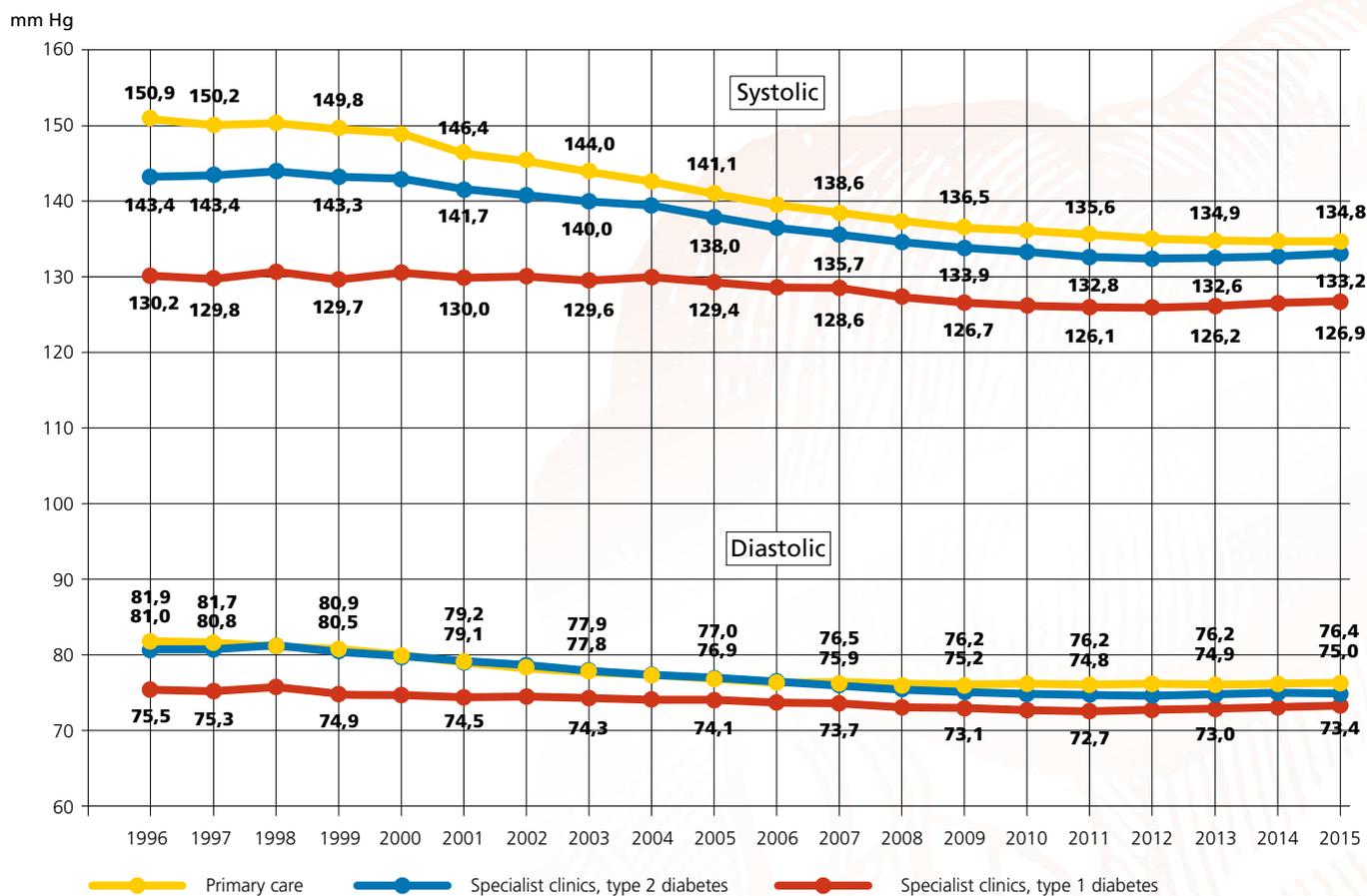
Source: NDR – Swedish National Diabetes Register

Histogram for systolic blood pressure (mm Hg). Patients with type 2 diabetes at specialist clinics. year 2015.



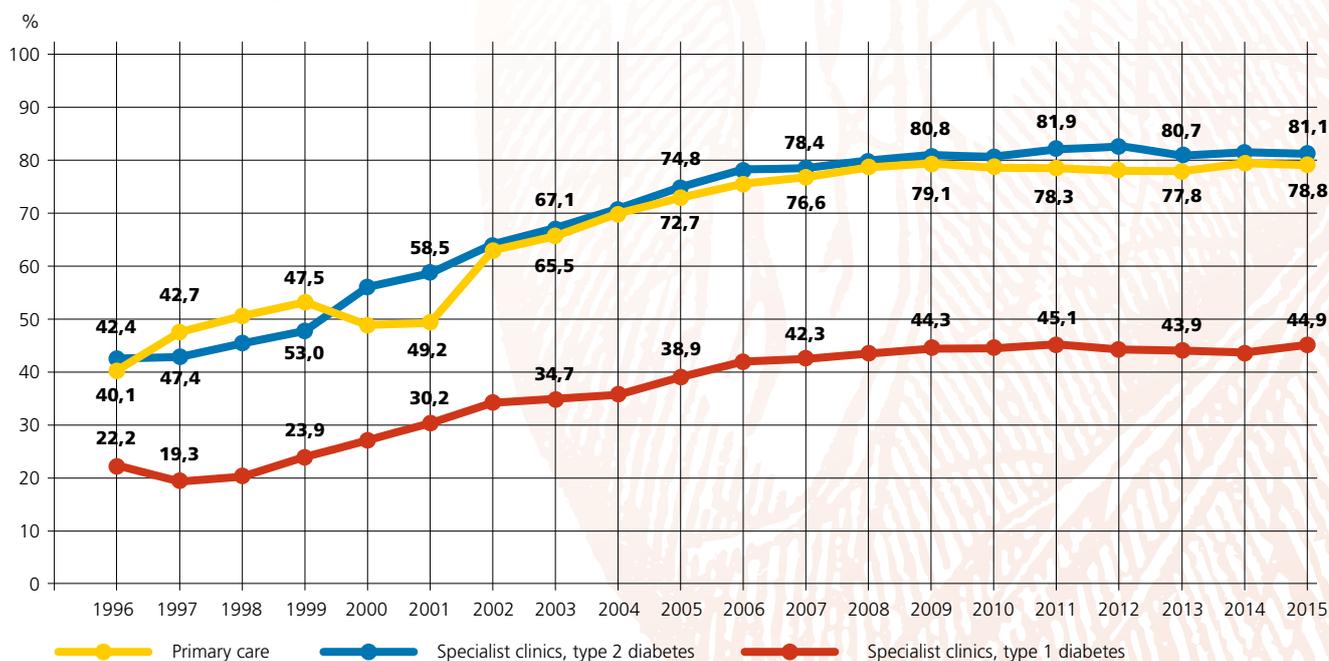
Source: NDR – Swedish National Diabetes Register

Mean blood pressure (mm Hg).



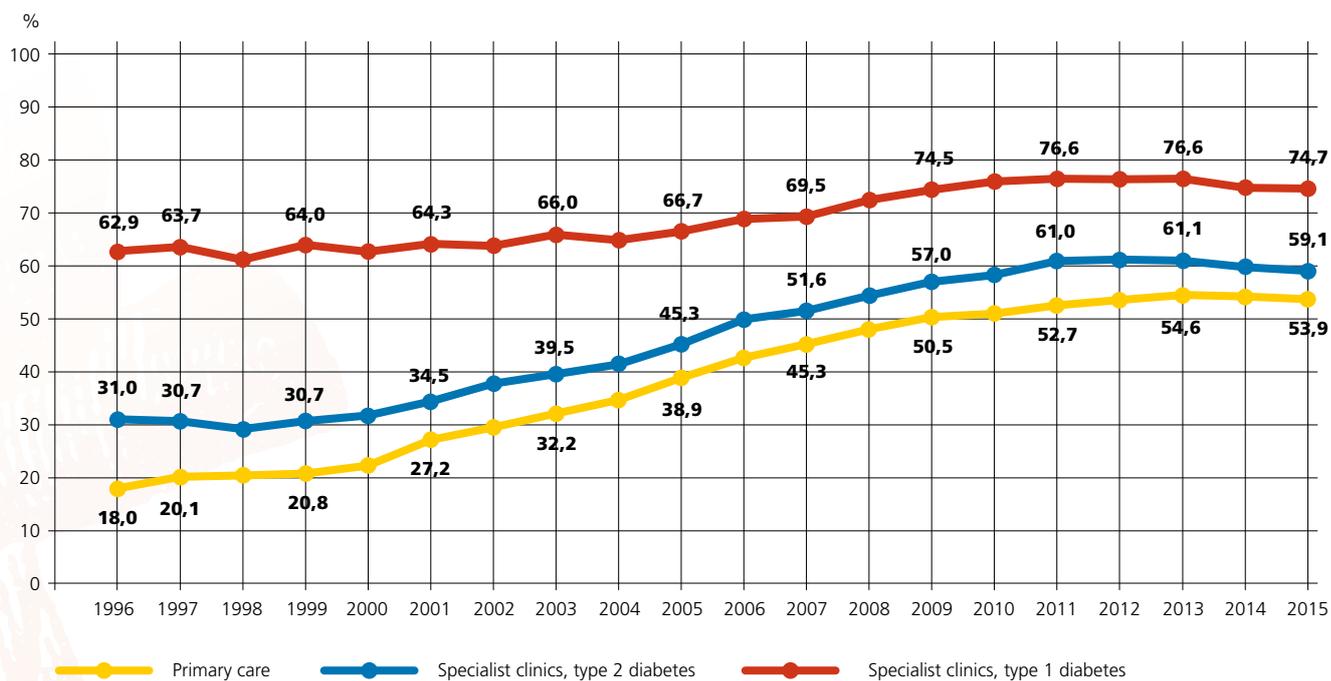
Source: NDR – Swedish National Diabetes Register

Antihypertensive drugs.



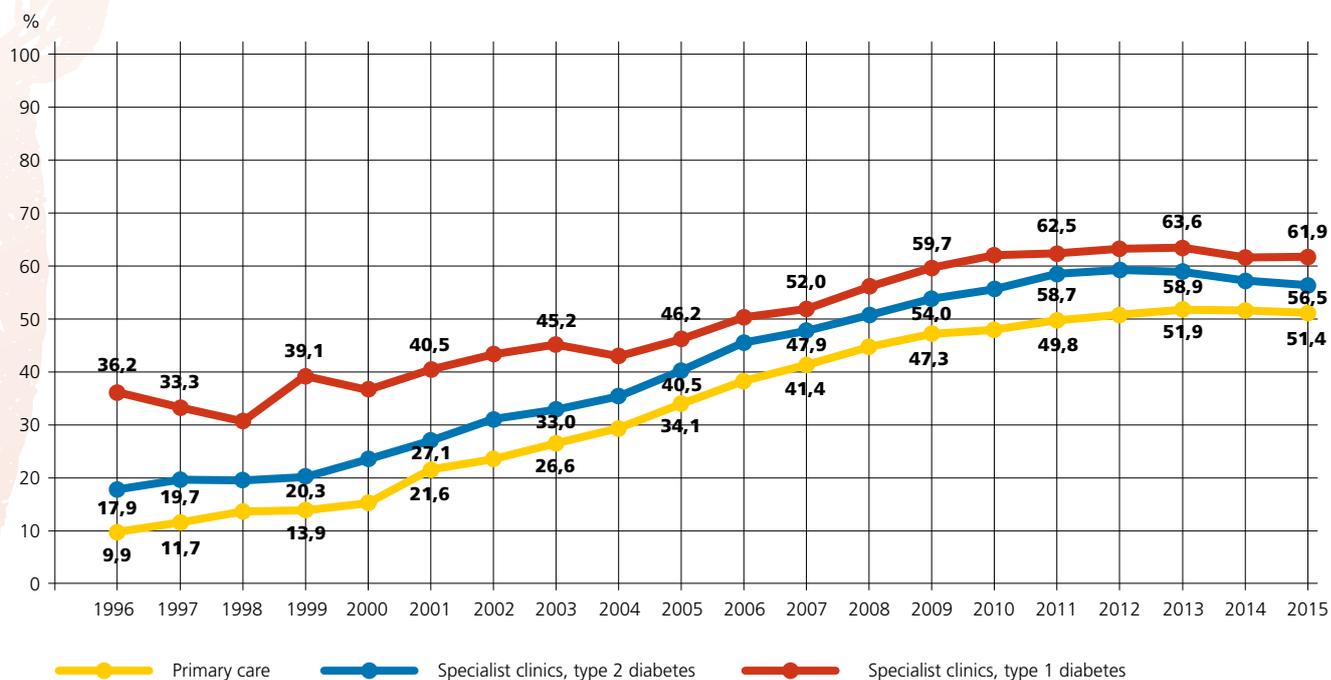
Source: NDR – Swedish National Diabetes Register

Blood pressure < 140/85 mm Hg.



Source: NDR – Swedish National Diabetes Register

Blood pressure < 140/85 mm Hg among patients treated with antihypertensive drugs.



Source: NDR – Swedish National Diabetes Register

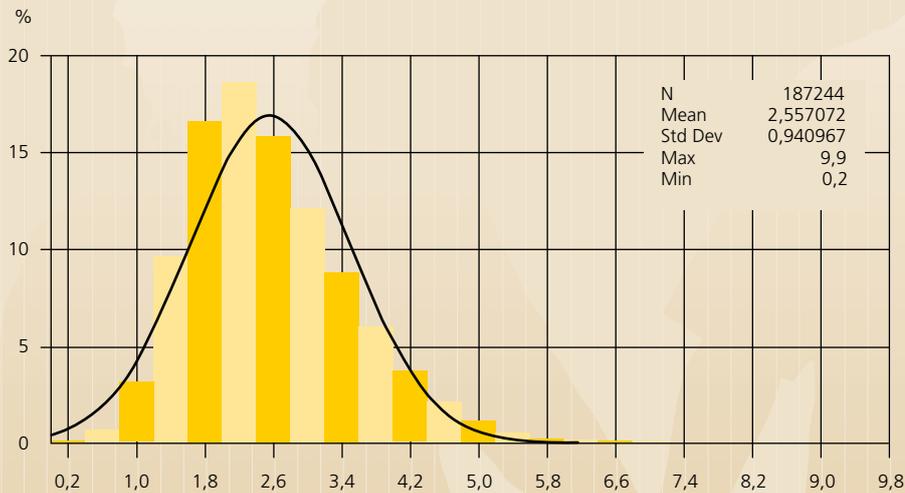
Blood lipids

The proportion of patients who achieved the target-level of LDL cholesterol (<2.5 mmol/L) almost doubled during the last decade. This trend is parallel with an increasing use of lipid-lowering medications.

Though the improvement is most pronounced for LDL cholesterol, the trends are also evident for HDL and total cholesterol. Triglyceride levels (not showed), which are not significantly affected by statin treatment, are unchanged among all patient populations. With the exception of patients

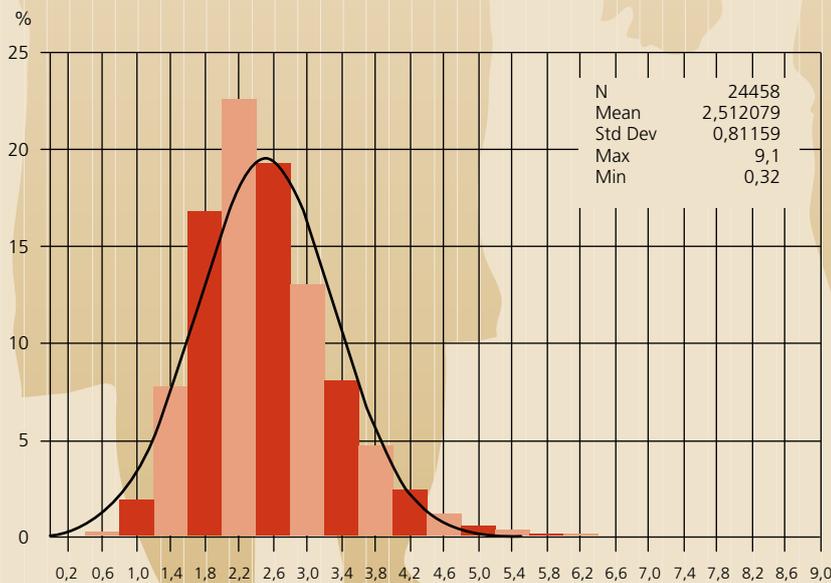
with type 2 at specialist clinics. Notably, the increase in use of lipid lowering treatment has levelled off in recent years. Altogether almost half of all patients have LDL cholesterol levels above 2.5 mmol/l in 2015.

Histogram for LDL (mmol/l). Patients with diabetes in primary care, year 2015.



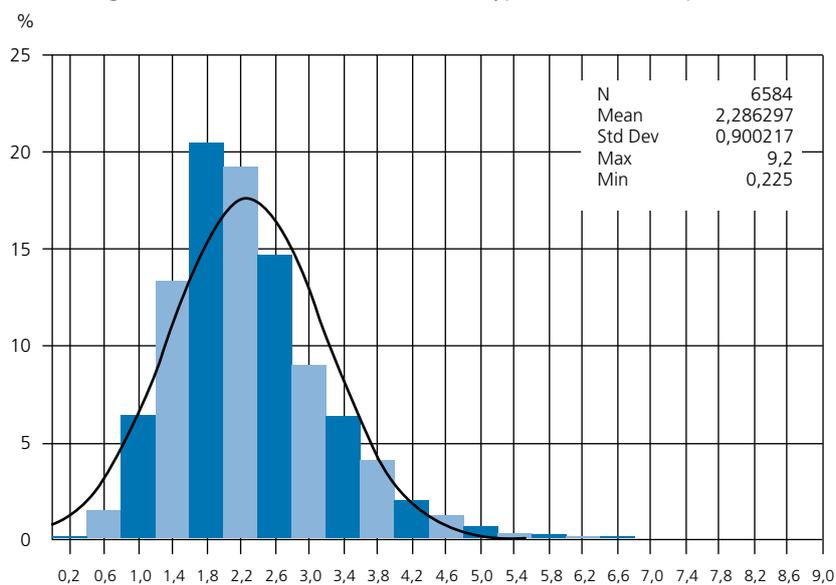
Source: NDR – Swedish National Diabetes Register

Histogram for LDL (mmol/l). Patients with type 1 diabetes at specialist clinics, year 2015.



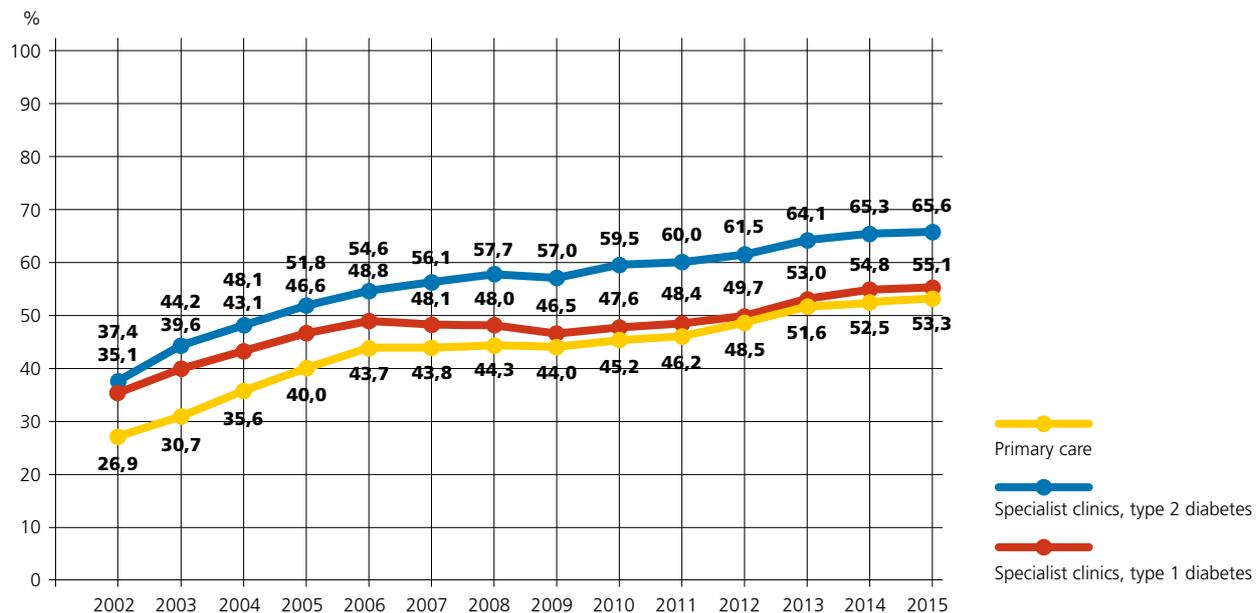
Source: NDR – Swedish National Diabetes Register

Histogram for LDL (mmol/l). Patients with type 2 diabetes at specialist clinics, year 2015.

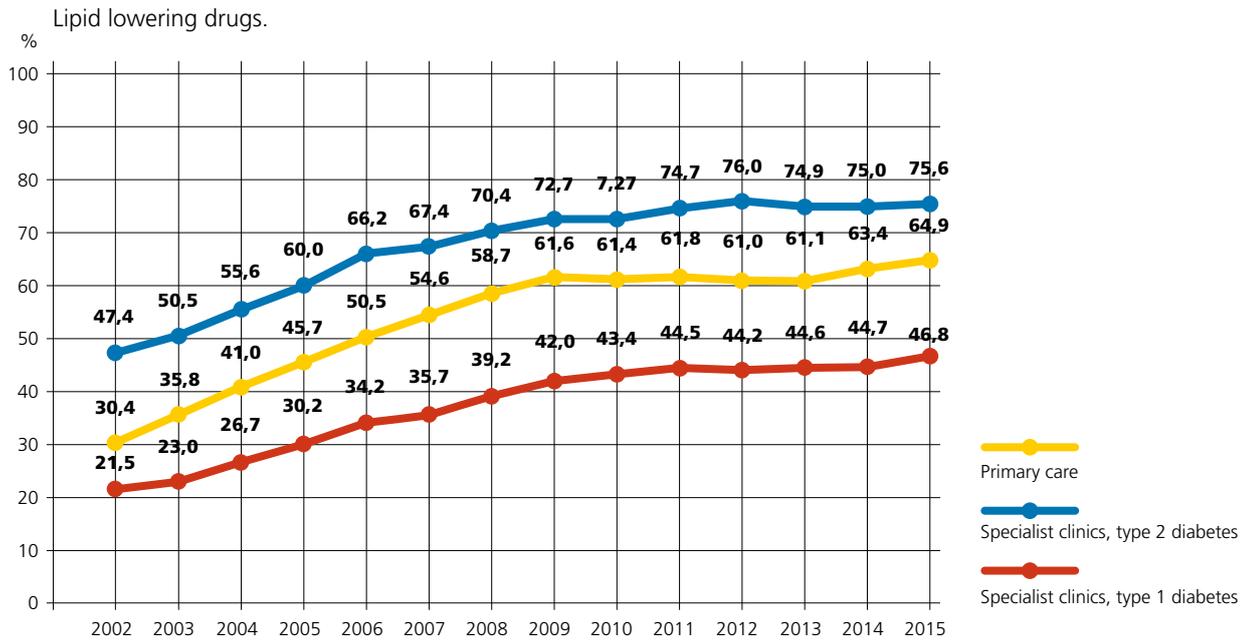


Source: NDR – Swedish National Diabetes Register

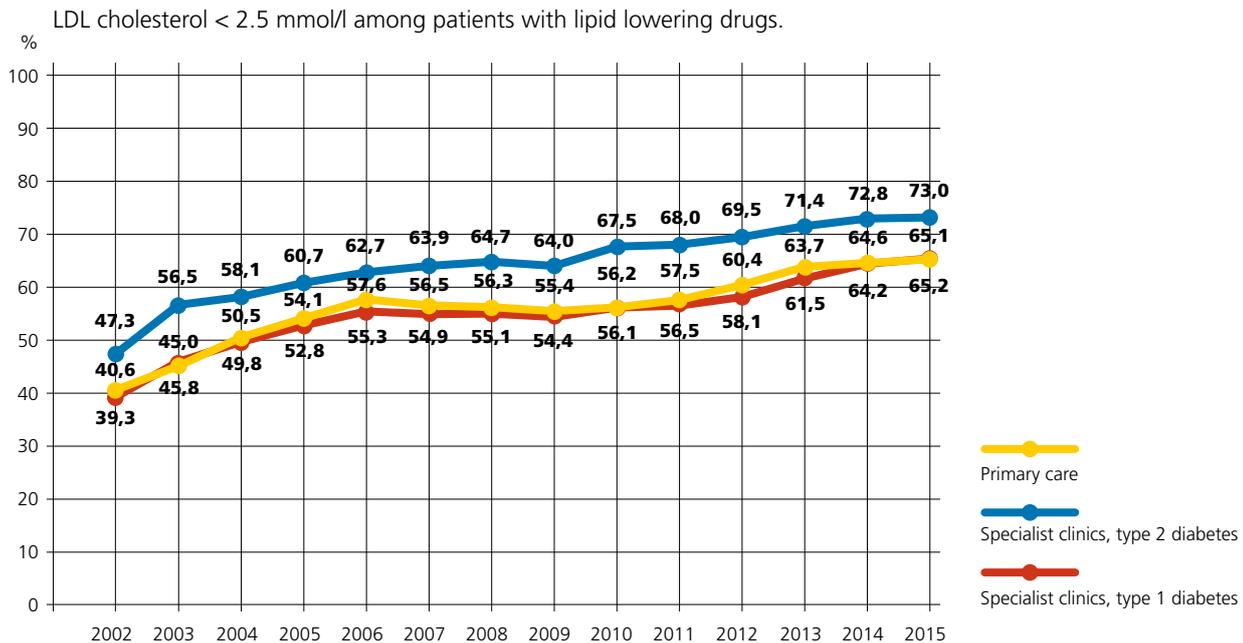
LDL cholesterol < 2.5 mmol/l.



Source: NDR – Swedish National Diabetes Register



Source: NDR – Swedish National Diabetes Register



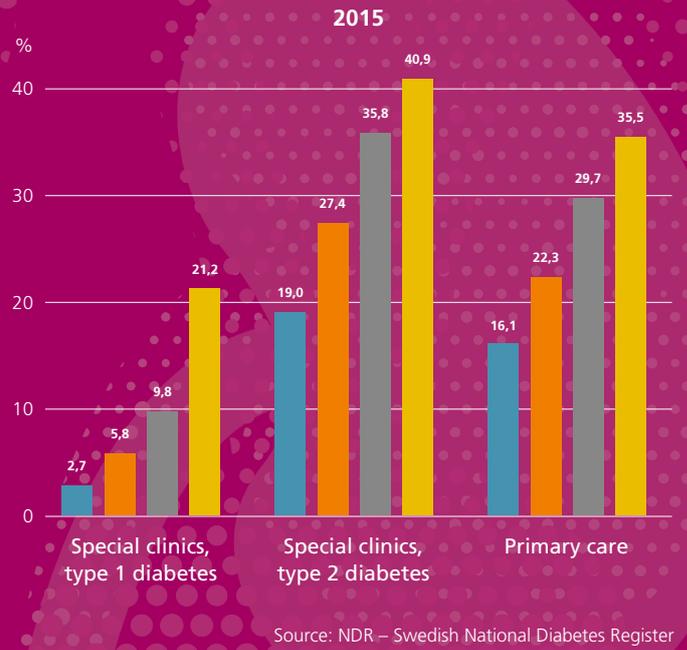
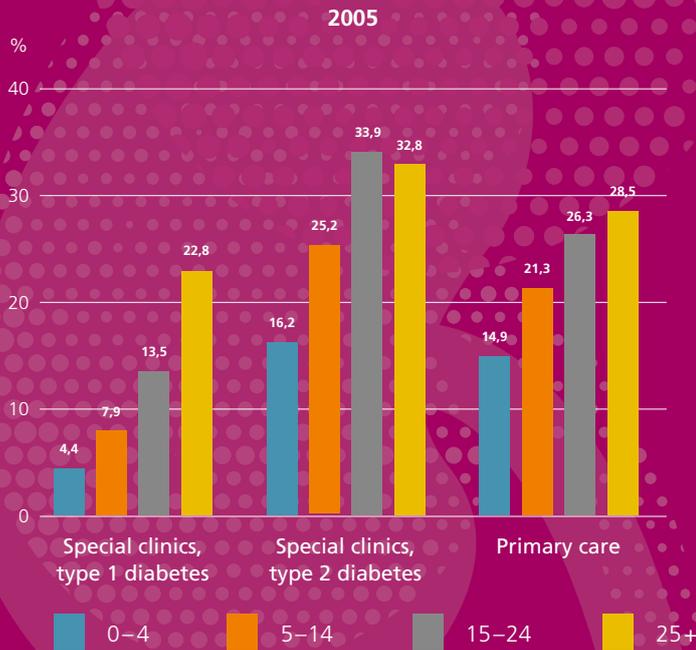
Source: NDR – Swedish National Diabetes Register

Impact on the kidneys

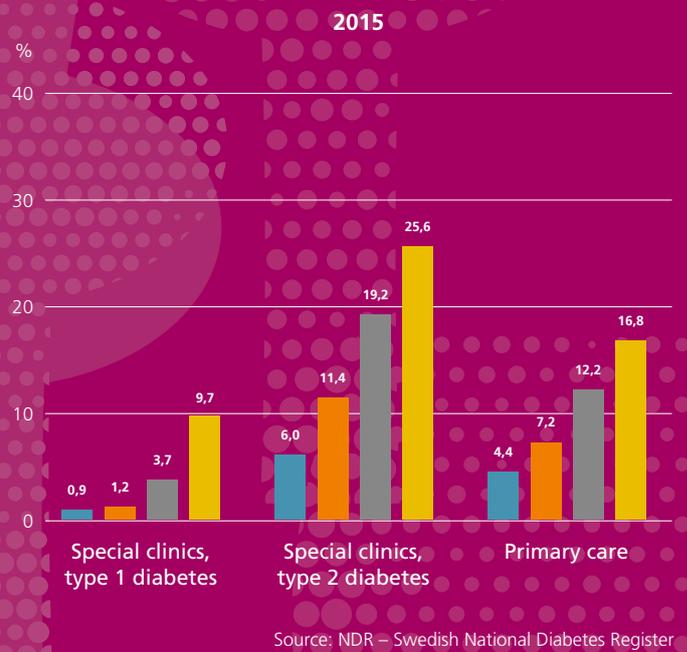
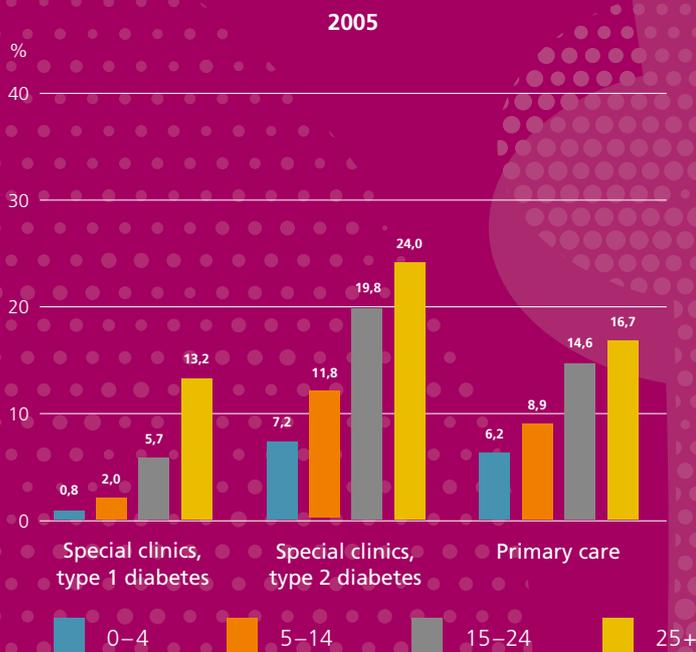
Almost one out of every five patients in primary care and more than one out of every ten patient with type 1 diabetes have

microalbuminuria. The proportion of micro- and macroalbuminuria cases rises in parallel with increasing diabetes duration.

Microalbuminuria (urine albumin excretion 20–200 µg/min) by diabetes duration.



Macroalbuminuria (urine albumin excretion > 200 µg/min) by diabetes duration.



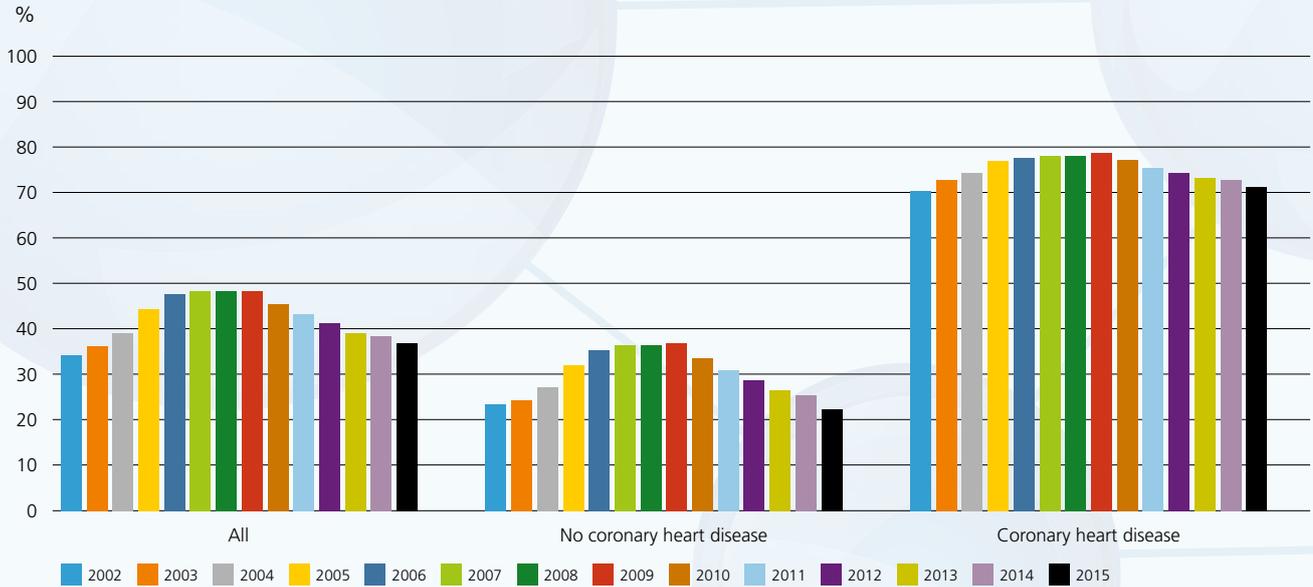
Acetylsalicylic Acid

The figures present the use of acetylsalicylic acid (aspirin). Treatment with aspirin has gradually declined for

both patients with type 1 and type 2 diabetes without ischaemic heart disease. Use of aspirin remains high for

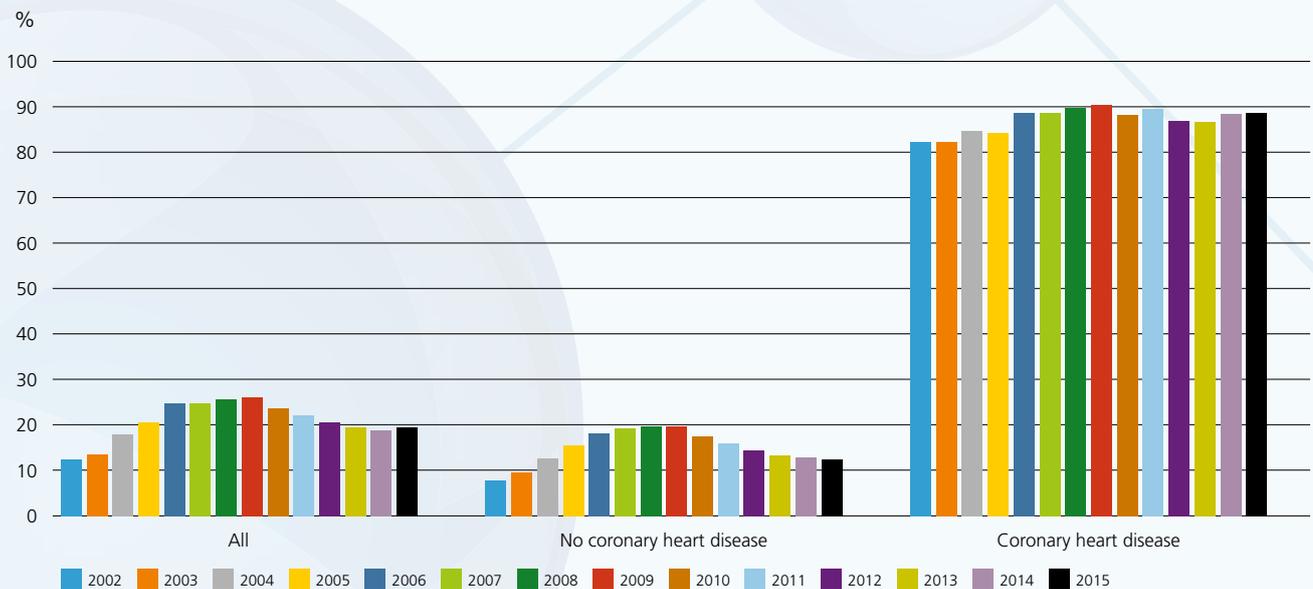
patients with ischaemic heart disease.

Acetylsalicylic acid for all patients and for patients with and without coronary heart disease. Primary care.



Source: NDR – Swedish National Diabetes Register

Acetylsalicylic acid for all patients and for patients with and without coronary heart disease. Type 1 diabetes at specialist clinic.



Source: NDR – Swedish National Diabetes Register

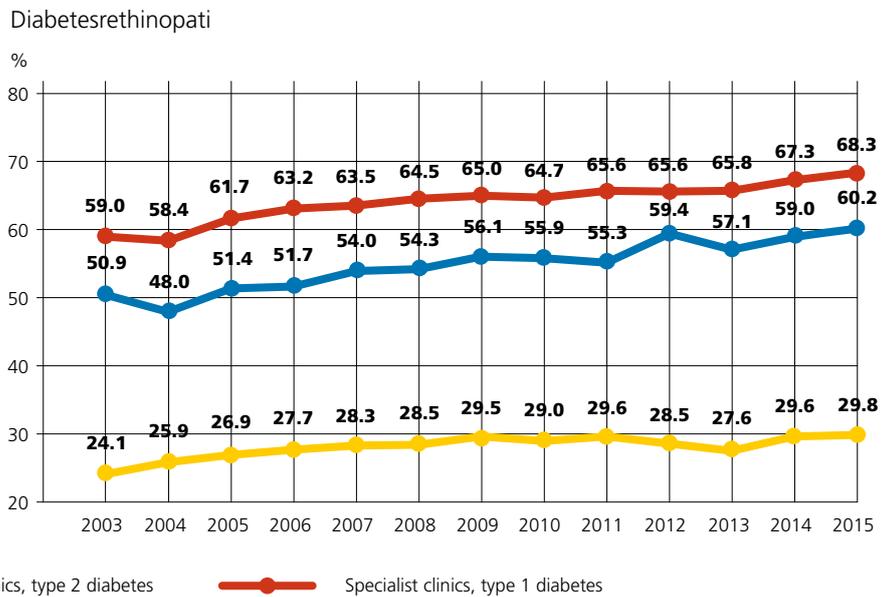
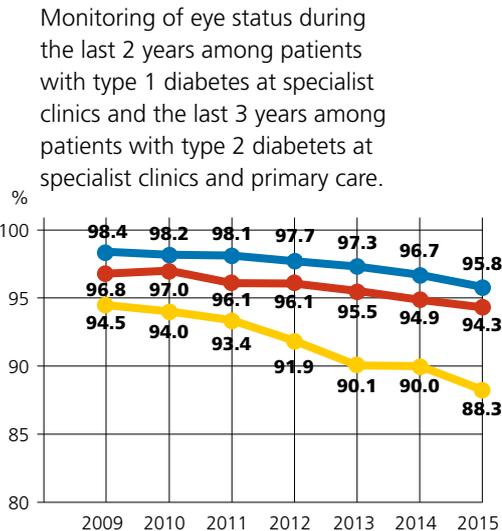
Process Measures

Eye and Foot Examinations

The national guidelines for diabetes care recommend a fundus examination every other year for patients with type 1 diabetes and every three years for patients with type 2 diabetes, or

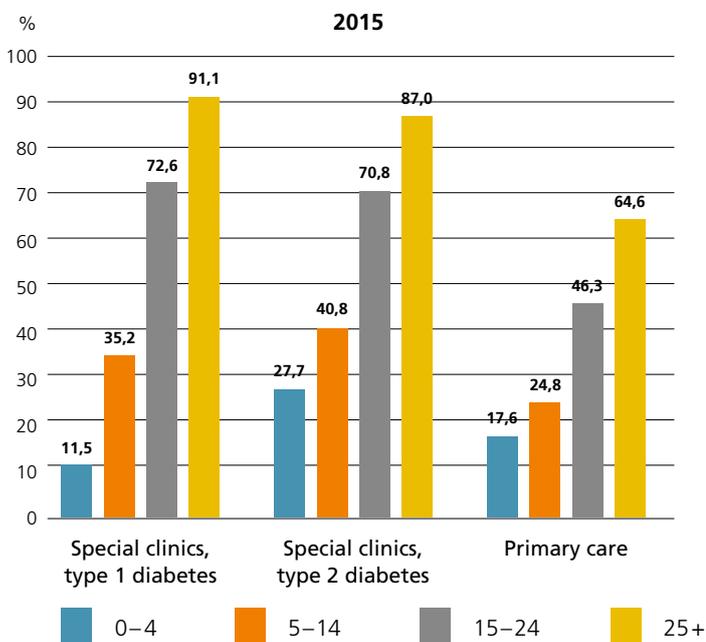
every year for patients with diabetes retinopathy. The figure shows that specialist clinics are examining almost the same percentage of patients as before (94.3% of type 1 diabetes and 95.8%

of type 2 diabetes) while primary care clinics are tending to examine somewhat fewer (88.3%). Approximately 93–95% of patients have had their foot examination done .

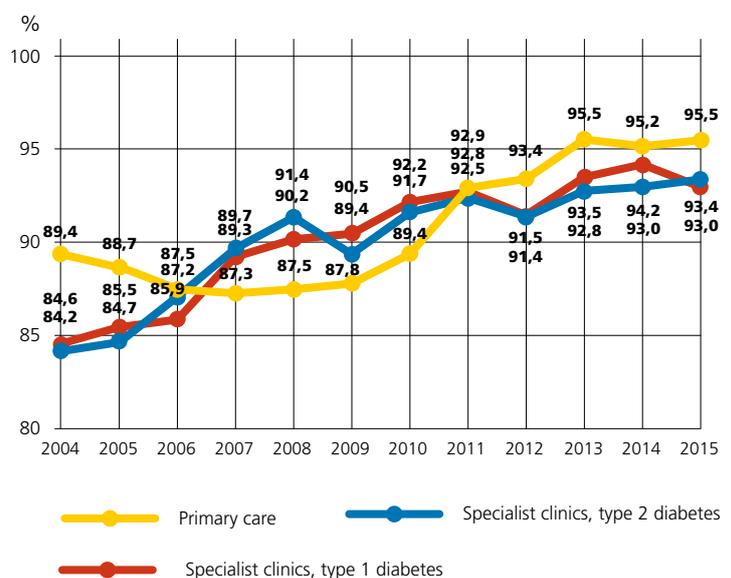


Source: NDR – Swedish National Diabetes Register

Diabetesretinopati by diabetes duration.



Monitoring of foot status during the last year.



Source: NDR – Swedish National Diabetes Register

Estimated 5-year Risk for Cardiovascular Disease

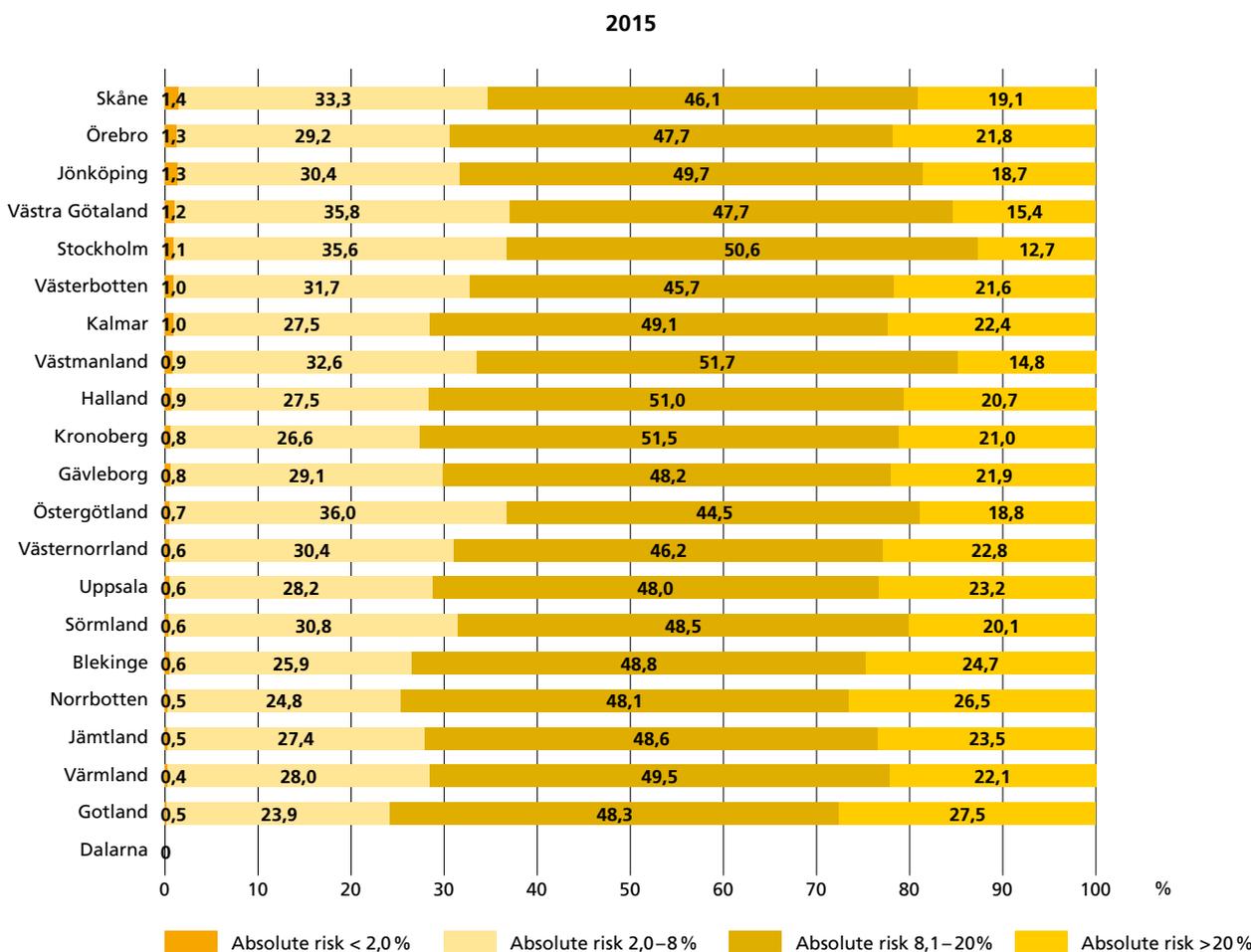
Based on the NDR risk model for type 1 and type 2 diabetes, these figures shows a county-by-county break down of absolute risk of developing cardiovascular disease (myocardial infarct/ stroke) in 5 years in 2015. The model proceeds from 12 cardiovascular risk factors: duration of diabetes, HbA1c

levels, systolic blood pressure, total cholesterol levels, HDL cholesterol levels, smoking, BMI, microalbuminuri, macroalbuminuri, previous cardiovascular disease, age and gender.

We have also calculated a normal risk – the absolute risk of someone of the patient’s age, gender and disease

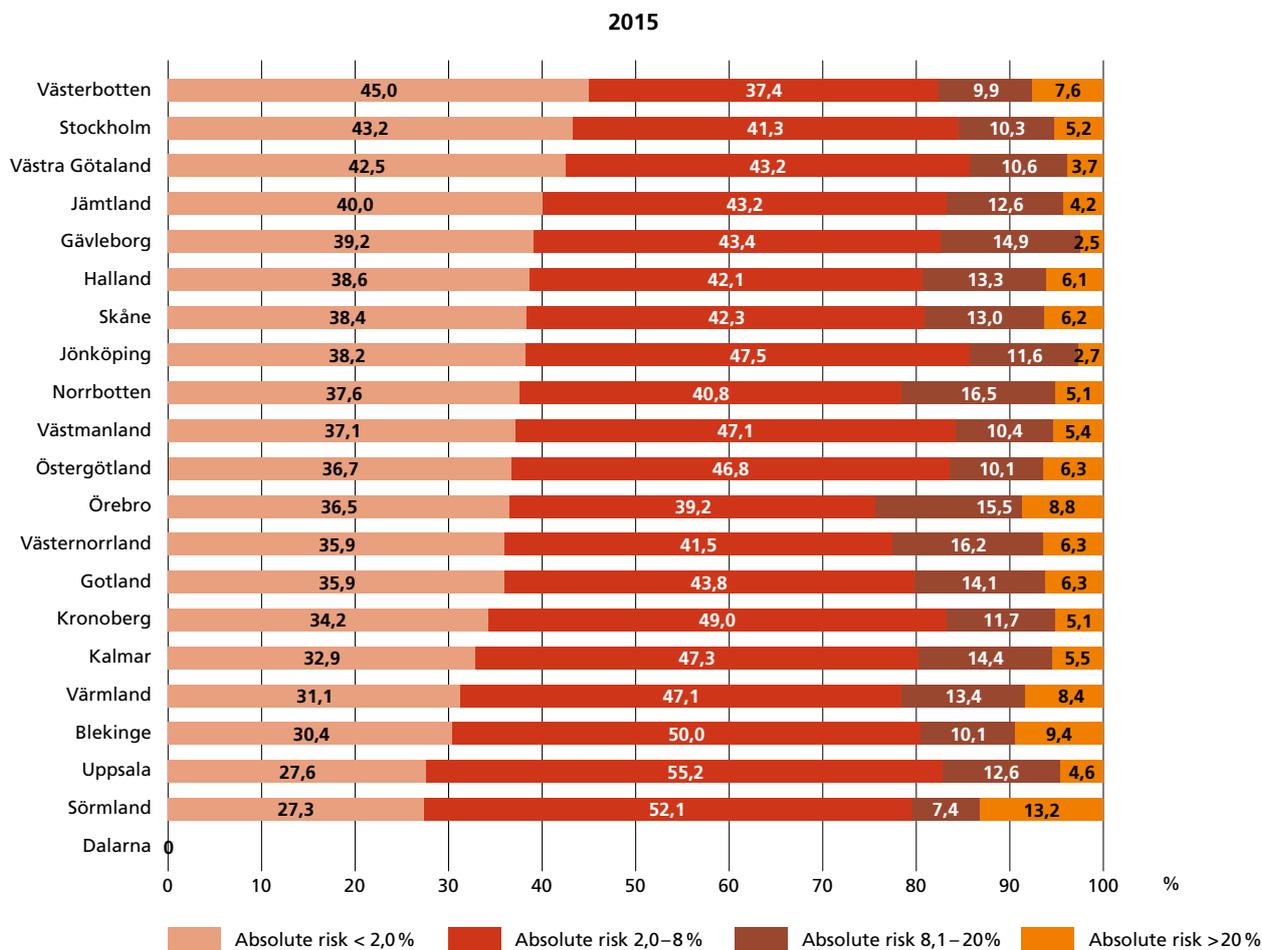
duration who has achieved normal levels for the modifiable risk factors: HbA1c (53 mmol/mol), systolic blood pressure (130 mmHg), total cholesterol (4.4 mmol/l), HDL cholesterol (1.1 mmol/l), BMI 25 kg/m², no proteinuria and nonsmoker. (Publications on page 54, Cederholm et al. ^{64, 81})

5-year risk for cardiovascular disease, NDR risk model. Patients in primary care age 30–79 by country.



Source: NDR – Swedish National Diabetes Register

5-year risk for cardiovascular disease, NDR risk model.
 Patients with type 1 diabetes at specialist clinic age 30–65 by country.



Source: NDR – Swedish National Diabetes Register

Facts about the NDR

Integral part of the Swedish diabetes care

The Swedish Association for Diabetology (SFD) established the National Diabetes Register (NDR) in 1996 in response to the St. Vincent Declaration, whose purpose was to persuade European countries to reduce the prevalence of diabetes complications. The NDR was designed to enable comparisons between the results achieved at all clinics treating diabetics and the nationwide average for a number of clinical variables. The register offers online tools for comparisons over time, as well as among counties and clinics. The tools are intended for use as part of local improvement efforts.

The NDR has become integral to Swedish diabetes care, particularly since the late 1990s as research has increasingly demonstrated the importance of various risk factors for diabetes complications and cardiovascular disease, not to mention the efficacy of new treatments for high blood pressure, blood sugar and blood lipid levels. Thus, the register meets the indispensable need for an instrument that monitors treatment outcomes.

How the NDR is structured

The SFD runs the NDR on behalf of the Swedish Association of Local Authorities and Regions. The register is financed by appropriations from the Executive Committee for National Quality Registers and the the Västra Götaland

Register Centre. Refer to www.ndr.nu for the NDR regulations.

NDR Steering Committee

- Mona Landin Olsson, Associated Professor, President of the Swedish Association for Diabetology (Convenor), Lund University
- Fredrik Löndahl, President of the Swedish Diabetes Association
- Soffia Guðbjörnsdóttir, Professor, Director of the Swedish National Diabetes Register, Gothenburg
- Karin Åkesson, MD, PhD, Director of the Swedish National Diabetes Register for Children and Adolescents (SWEDIABKIDS), Department of Paediatrics, Ryhov County Hospital, Jönköping

Representatives of:

- Swedish Society of Endocrinology: Professor Mikael Rydén, Karolinska University Hospital, Huddinge
- Representative of primary care: Kristina Bengtsson Boström, Associate Professor, Billingen Health Centre, Skövde
- Section for Endocrinology and Diabetes, Swedish Association of Paediatricians: Karin Åkesson, MD, PhD, Director of the Swedish National Diabetes Register for Children and Adolescents (SWEDIABKIDS), Department of Paediatrics, Ryhov County Hospital, Jönköping

- Swedish Association of Diabetes Nurses: Ingela Bredenberg, Karolinska University Hospital, Stockholm
- Swedish National Diabetes Register: Pär Samuelsson, Development manager

Research group

The Research group is responsible for processing NDR data, as well as compiling annual and scientific reports for national and international conferences. The committee also promotes the use of the data in clinical research. The NDR has published a number of its scientific reports in national and international journals over the past few years.

- Soffia Guðbjörnsdóttir, Professor
- Jan Cederholm, Associate Professor
- Björn Eliasson, Professor
- Katarina Eeg-Olofsson, MD, PhD
- Björn Zethelius, Associate Professor
- Ann-Marie Svensson, Associate Director, PhD
- Mervete Miftaraj, Biostatistician, MSc
- Stefan Franzén, Biostatistician, PhD

NDR Staff:



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Ann-Marie Svensson, Associate Director, PhD



Pär Samuelsson, Development manager



Ebba Linder, Development manager



Ia Almskog, Coordinator



Mervete Miftaraj, Biostatistician, MSc



Stefan Franzén, Biostatistician, PhD



Henrik Milefors, System developer

Photo: Charlotta Sjöstedt

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NDR: the flagship register for Swedish diabetes care

- Enters an average of *1,400 patients daily* as reported by thousands of healthcare providers.
- Offers a clinical tool for risk assessment, monitoring and comparison.
- Promotes improvement through measurement.
- Encourages clinical research with a focus on patient benefit.



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