



Deliverable 2.4.1

Patient Information Material

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Document History

Version	Date	Changes	From	Review
V0.1	10.03.2014	Initial Document	USI	All Partners
V0.2	18.03.2014	SRFG comments	SRFG	
V1.0	26.03.2014	Integration of partners' comments and missing parts	USI	

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Abbreviations

ODL	Observations of Daily Living
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1 Executive Summary

This deliverable illustrates the idea behind the development of the Patient Information Material for EMPOWER, the production and the implementation of the English version, the translation and the adaptation of the material in German and Turkish, and finally their implementation. Screenshots from all the three versions of the Patient Information Material exemplify the structure of the website and the way the information is presented.

2 EMPOWER in a Nutshell

Patient Empowerment involves patients to a greater extent in their own healthcare process and disease management becomes an integrated part of their daily lives. The capability of self-management opens to them the possibility for patients not only to contribute to their own healthcare but also to be more in control of their disease. EMPOWER develops a modular and standard-based Patient Empowerment Framework which facilitates the self-management of diabetes patients based on PHRs and on context-aware, personalised services. EMPOWER focuses the research and development efforts on a patient-centric perspective that also involves healthcare professionals. EMPOWER provides knowledge-based Self-Management Pathways for diabetes patients. This includes

- (1) Services for the specification and execution of actions to change behaviour according to diabetes-specific health care needs. Patients can develop personalised action plans which include recommendations from the treating physicians and patients' preferences
- (2) Services for monitoring of vital, physical, mental parameters as well as physical and lifestyle activities based on health standards.



EMPOWER semantically integrates multiple information sources (EHR/PHR, diabetes guidelines, patterns of daily living) for a shared knowledge model. The Self-Management Pathways facilitate the specification of recommendations that allow specifying individual goals for the patient. Based on these goals, relevant information and their preferences patients can specify their individual diabetes-specific actions. The Self-Management Pathways are an iterative process where executed actions and reported patterns of daily life can be evaluated. Recommendations, goals and actions can be updated iteratively according to current needs and preferences. Finally, the services in EMPOWER will embrace semantic interoperability based on health standards such as HL7¹ and IHE² profiles.

EMPOWER addresses long-term goals and short-term activities in order to facilitate the self-management of patients with diabetes and thus the treatment of chronic diseases. The pilot applications in Germany and Turkey will demonstrate that the holistic and patient-centric

¹ <http://www.hl7.org>

² <http://www.ihe.net>

approach of EMPOWER can improve disease management by personalised self-management services helping diabetes patients to cope better with their condition.

3 Background rationale

EMPOWER Patient Information Material is designed to give to the user a space where he can gather the information he needs in relation to diabetes. Since patients suffering from diabetes have different level of knowledge, the material is designed to address different information needs: from basic information to more detailed, and from generic information to practical advice. For this purpose the Patient Information Material has been structured along three levels of content:

1. Level 1: Knowledge
2. Level 2: Management
3. Level 3: Advice

These three levels are structured along the health literacy and empowerment model presented in deliverable D2.1.1 (Schulz and Nakamoto 2013). Patient Information material has been divided into nine chapters, each of which is structured in: Heading, Abstract, Text including figures, and Tags. All of the chapters have both level 1 and level 2 contents, while level 3 is only available in some specific chapters. The content level have been distinguished not just in the writing phase, but also in the implementation phase by distinguishing the levels into different menus.

The picture below illustrates the title of the nine chapters and the three content levels. This picture was presented to the partners before implementing the prototype version of the Patient Information Material.



Figure 1: Original Patient Information Material structure presented to the partners beginning of Year II

3.1 Content level 1: Knowledge (Declarative Knowledge)

This section provides basic information needed by the patient to understand the illness, its treatment and daily life with it. The question behind each content covering this content level is: What is it? This level of content is related to the part of health literacy called *declarative knowledge*: factual knowledge related to health issues to be able to learn how to approach a health condition.

This first level of content is exemplified by the following text extracted from the Nutrition chapter:

Nutrition

Diabetes mellitus is a metabolic disorder. An important goal for diabetes patients therefore is to bring nutrition, physical activity and medical therapy into balance. Here you may find useful insights on calories, nutritional facts, and also some advice on your eating plan, eating out, and how to have tasty meals.

Why should we care about nutrition?

People suffering from Diabetes Type 1 or Type 2 only can use the food they eat for physical and mental benefits if the blood glucose levels are correct.

In order to manage the disease effectively it is important to be well-informed about nutrition and its possible effects on the metabolism.

3.2 Content level 2: Management Behavior (Procedural Knowledge)

This second section provides more targeted information concerning the management of diabetes, its symptoms and complications. The question behind each content covering this content level is: How to do that? This level of content is related to the part of health literacy called *procedural knowledge*: “know-how” to apply factual knowledge and use health information in a specific context.

This second level of content is exemplified by the following text extracted from the Nutrition chapter:

The right balance in nutrition is important!

Together with physical activity and treatment, healthy eating is one of the most important parts of diabetes management. Sometimes you may be concerned with specific ingredients that may affect your blood sugar level, but you must remember the overall picture. You shouldn't be excessive with quantities and you should stick to a schedule. Here you'll find some suggestions on how to balance your nutrition: **Keep to a schedule.** Eating at the same time every day helps to maintain stable blood sugar levels. As you monitor your levels you should be able to recognize patterns: the blood sugar levels is highest after eating and decreases after a couple of hours.

Make every meal well-balanced. Try to cook or order food with the right mix of nutrients (starches, fruits and vegetables, proteins, and fats). Remember that carbohydrates are particularly important, and try to eat the same amount of them at each meal.

Eat the right amount of foods. Try to divide the food into portion sizes. Keep track of portions for your typical food thus to simplify the process. Be precise by using a scale or any appropriate measurement tool.

Coordinate your meals and medication. Be aware that if you are eating too little or too much this can be dangerous. You should also balance the quantity of food you eat with your medication intake.

These suggestions could be more safely implemented in your routine if initiated with your dietitian or your doctor!

3.3 Content level 3: Management Advice (Judgment Skills)

The third section of contents won't be always present. Only when some special situation can be described in order to make the patient understand what he should do. The question behind each content covering this content level is: What to do if? This level of content is related to the part of health literacy called *judgment skills*: the ability to judge on the basis of factual knowledge necessary to deal with novel situations.

This third level of content is exemplified by the following text extracted from the Nutrition chapter:

I love sweets, but I know I have to cut them from my diet...

Reconsider your definition of sweet

Diabetes nutrition doesn't have to mean no sweets. If you're craving them, ask a registered dietitian to help you include your favorite treats into your meal plan. A dietitian can also help you reduce the amount of sugar and fat in your favorite recipes. Don't be surprised if your tastes change as you adopt healthier eating habits. Food that you once loved may seem too sweet — and healthy substitutes may become your new idea of delicious.

4 Development of Material

Aside from the distinction among the content levels, which has been explained in the previous paragraphs, some guidelines for text production have been derived from MedlinePlus (U.S. National Library of Medicine). These Guidelines have been shared with the partners who had the responsibility for the translation of the material, which have been entirely developed in English. The guidelines are the following:

General Points

- I Keep within a range of about a 6th to 7th grade reading level.

- | Focus on a 2-3 key concepts.
- | Use a clear topic sentence at the beginning of each paragraph. Follow the topic sentence with details and examples.
- | Examples and stories may help engage readers. Use words like "you" instead of "the patient."
- | Include your most important points at the beginning of the document.
- | Avoid abstract words in instructions for actions. For example, instead of "Don't lift anything heavy," use "Don't lift anything heavier than a gallon of milk (over about 10 pounds)."
- | Emphasize the benefits of the desired behavior.

Language and writing style

- | Find alternatives for complex words, medical jargon, abbreviations, and acronyms.
- | Keep most sentences 10-15 words long.
- | Where appropriate, use bulleted lists instead of blocks of text to make information more readable.
- | Use the active voice and vivid verbs.

Active: Amanda used her inhaler today.

Passive: The inhaler was used by Amanda today.

- | Be consistent with terms. For example, don't use "drugs" and "medications" interchangeably in the same document.
- | When possible, say things positively, not negatively.

Visual Presentation and Representation

- | Use illustrations and photos with concise captions. Keep captions close to photos and illustrations.
- | Balance the use of text, graphics, and clear or "white space". Try for 40-50% white space.
- | Avoid using all capital letters. Upper and lower case are easier to read. To show emphasis, use bold, larger type size or different fonts.
- | Avoid italics of more than a few words at a time.
- | Use easy to read fonts such as Times Roman, Arial, Tahoma and Helvetica.
- | Use bolded headings and subheadings to separate and highlight document sections.
- | When possible, use graphics or spell out fractions and percentages.
- | Use column widths of about 30-50 characters long (including spaces) or 3 to 5 inches.

4.1 Description of Sources

As it was agreed to develop a first version of the patient information material in English most of its development was based on already existing sources in English language. Most of the sources were originated in the United States where diabetes information material can be accessed via online libraries of various institutions. Among these institutions were the American Diabetes Association (ADA) and the Mayo Clinic.

In addition, printed material was used that had been recommended by GOIN and other members of the project.

One limitation of this approach was that content was developed detached from country specificities. If country differences were taken into account it was rather developed for the German context than for the Turkish due to language issues. In order to answer to this problem the involved doctors in Germany and Turkey were asked to review the information material carefully before the translation took place. In addition, GOIN and MoH were asked to also carefully go through the document during the translation process in order to adapt the content where necessary.

Once the translations were received and implemented in the system, open issues and translational problems were resolved through consultations with partners and involved staff.

Author/Authoring Organization	Title/Reference
Online Sources	
American Diabetes Association (ADA)	http://www.diabetes.org
Mayo Clinic	http://www.mayoclinic.org
National Diabetes Information Clearinghouse (NDIC)	http://diabetes.niddk.nih.gov/dm/pubs/eating_ez/
Diabetes Teaching Center at the University of California, San Francisco	http://dtc.ucsf.edu/living-with-diabetes/diet-and-nutrition/understanding-protein/
Diabetes UK	http://www.diabetes.org.uk
Printed Material	
Avery, L.: Beckwith, S.. Oxford University Press, 2009	Oxford Handbook of Diabetes Nursing
Bayer Diabetes Haus – Bayer Diabetes Service Bayer HealthCare	Diabetes mit Insulintherapie – Antworten auf häufig gestellte Fragen. Bayer HealthCare Diabetes Care Bayer Vital GmbH
Bayer Diabetes Haus – Bayer Diabetes Service Bayer HealthCare	Reisen mit Diabetes - Ein Ratgeber für Menschen mit insulinpflichtigem Diabetes.
Bergmann, K.: Berlin-Chemie Menarini	Diabetes mellitus – Was bedeutet das für Sie?
Bergman, K.; Bierwirth, R.A.: Berlin-Chemie Menarini	Reiselust und Insulinpflicht – Tipps für insulinpflichtige Diabetiker
Bühling, K.J.; Wäscher, C.; Dudenhausen, J.W.: Akademos Wissenschaftsverlag, 2013	Gestationsdiabetes – Ernährung i der Schwangerschaft
Fachkommission Diabetes Bayern E.V.	Gestationsdiabetes – Empfehlungen zum generellen Screening und zur Therapie
Lorig, K.: Gazelle Book Services, 2007	Self-Management of Long-Term Health Conditions: A Handbook for People with Chronic Disease
Ratzmann, A.: Berlin-Chemie Menarini	Diabetes und Zahngesundheit – Ein kleiner Ratgeber
SANOFI Diabetes; Sanofi-Aventis Deutschland GmbH	Mit Diabetes auf gutem Fuss – Informationen & Tipps für Menschen mit Diabetes und ihre Angehörigen
Siegel, E.; Schröder, F., Kunder, J.; Dreyer, M.: Börm Bruckmeier Verlag, 2012	Diabetes mellitus XXS pocket
Van de Roemer, A.: Vdm Verlag	Ihr Wegbegleiter Typ 2 Diabetes –

	Informationen für Patienten und Angehörige
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Table 1: Sources of EMPOWER Patient Information Material

4.2 Testing and adaptation of the material

The Patient Information Material was tested on four people, three of them suffering from diabetes 2 and one suffering from diabetes 1. Three of the patients were male around 50 years of age, while the fourth was a female 28 years old. The interviews lasted from a minimum of half an hour to a maximum of 56 minutes. They took place in January 2014 with the complete implemented English version. Patients were asked to use the website in order to look for some specific information. Three out of the four patients are regularly looking for health information on the internet, while the last one says that he prefer to ask experts about it (his doctor). All the patients agreed on assessing that the structure of the website is clear, the layout clean and simple, and that is quite easy how to navigate among the contents. However there were also some critics coming out, and particularly all of them say that they were unsure if to trust the information because the providers of the information were not declared. Some minor comments were referring to tags and the search option. They said that the search option was not so evident, and that the tags were misleading, because some words are written in a bigger font but they are not necessarily more important. One of the participants found the website boring, and all of them criticized the absence of images. Materials were partially adapted after this testing. The final adaptation will be made after the first validation phase, when information will be collected in terms of usability, perceived usefulness, barriers and enablers.

5 Implementation

Patient Information material has been implemented using the WordPress³ content management system (CMS). A total of 55 pages and 57 posts was produced in all the three languages.

USI provided the English text in a word file with an ID code for each part and a space for Turkish and German translation. USI provided the partners also with guidelines for text production and for the translation of Patient Information Material. MoH and GOIN provided the translated version of the material, and USI replicated the website for the new versions.

The WordPress CMS was chosen because the community and tool support, the documentation and in particular, portability. and WordPress content is very portable and the export documents can be imported by many alternative CMS systems. After the initial setup and training, content administrators were chosen who then managed other content authors during the implementation of the content.

The following sites were created for EMPOWER:

- EN - <http://empowerpatient.wordpress.com>
- DE - <http://empowerpatientde.wordpress.com>
- TR - <http://empowerpatienttr.wordpress.com>

Using the administrative tool, the original English site was exported to a Wordpress export file and then before translating the content, the file was imported into the two empty pilot sites (DE, TR) to create the site structure and enable WordPress functionalities used in the source site.

³ <http://wordpress.com/>

In the following paragraphs a series of screenshots will exemplify the Patient Information Material in the three languages: English, German and Turkish.

5.1 English Version

<http://empowerpatient.wordpress.com>

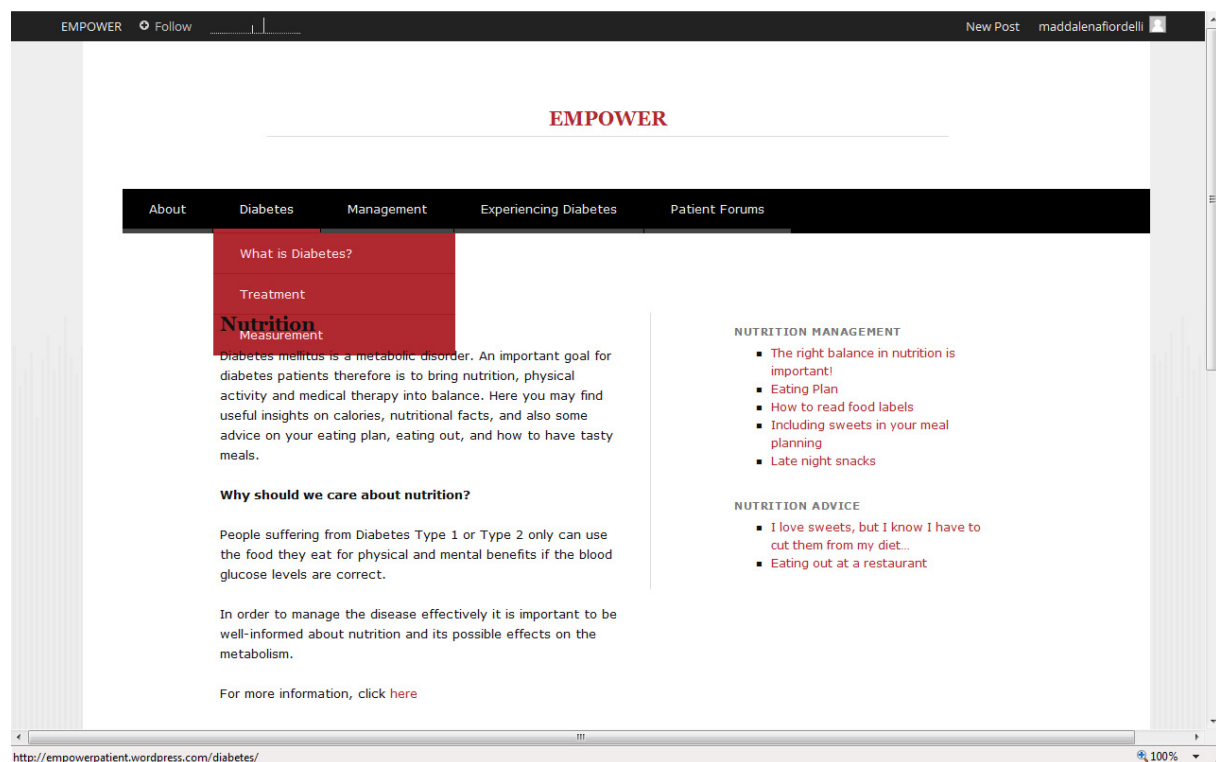


Figure 3: Diabetes submenu with the three information chapters: Diabetes, Treatment, Measurement

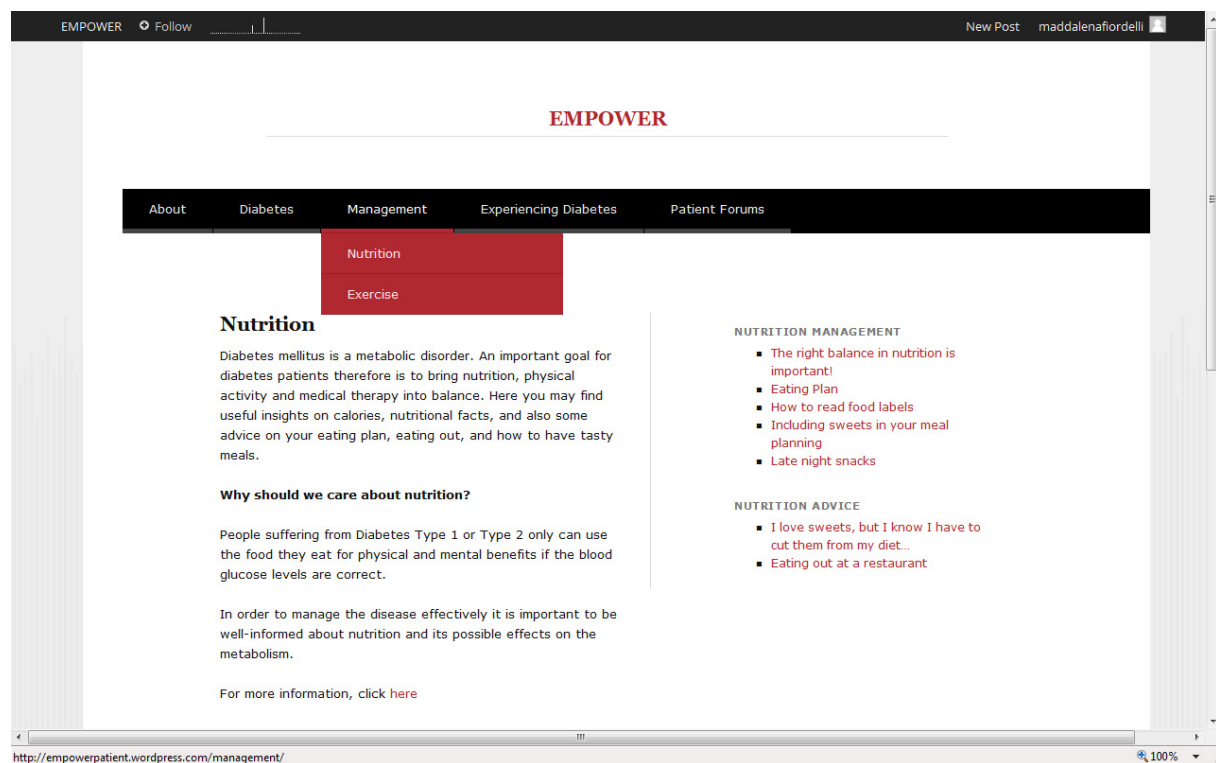


Figure 4: Management submenu with the two information chapters: Nutrition, Exercise

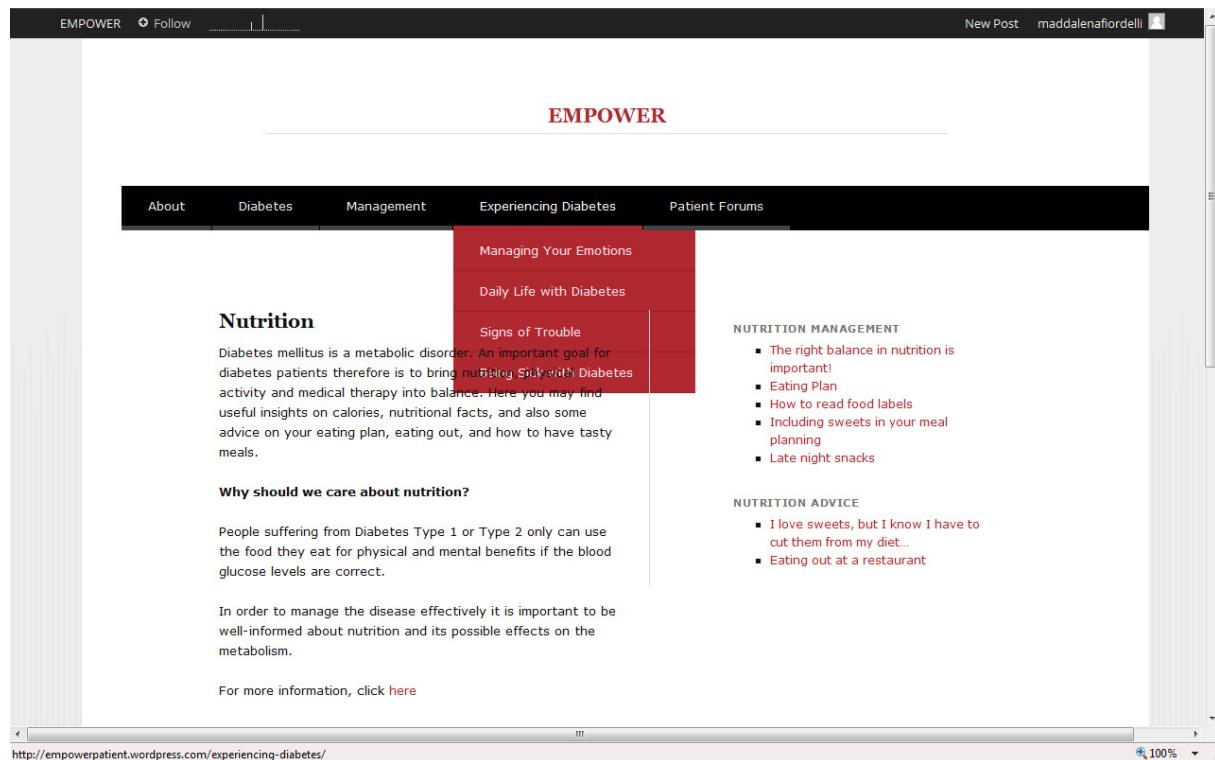


Figure 5: Experiencing diabetes submenu with the four information chapters: Emotions management, Daily life with Diabetes, Signs of Trouble, Being sick with Diabetes

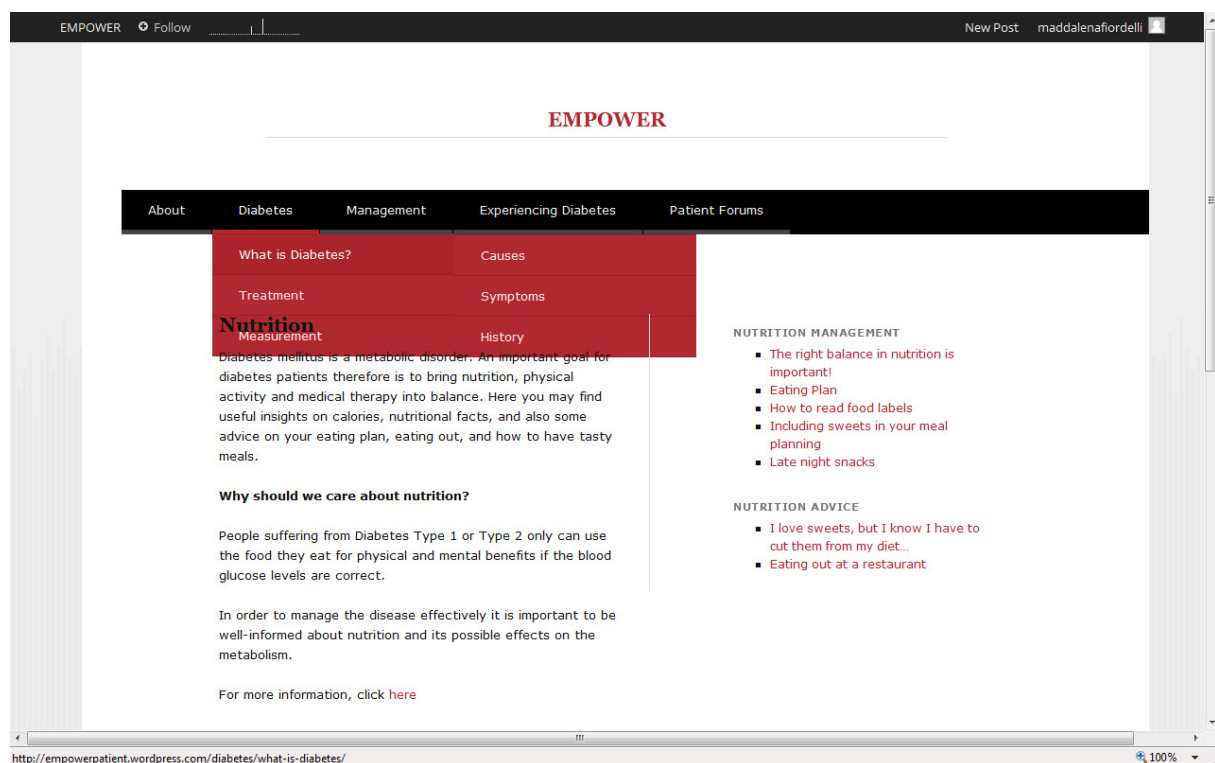


Figure 6: Submenu of the Diabetes Information chapter: Causes, Symptoms, History

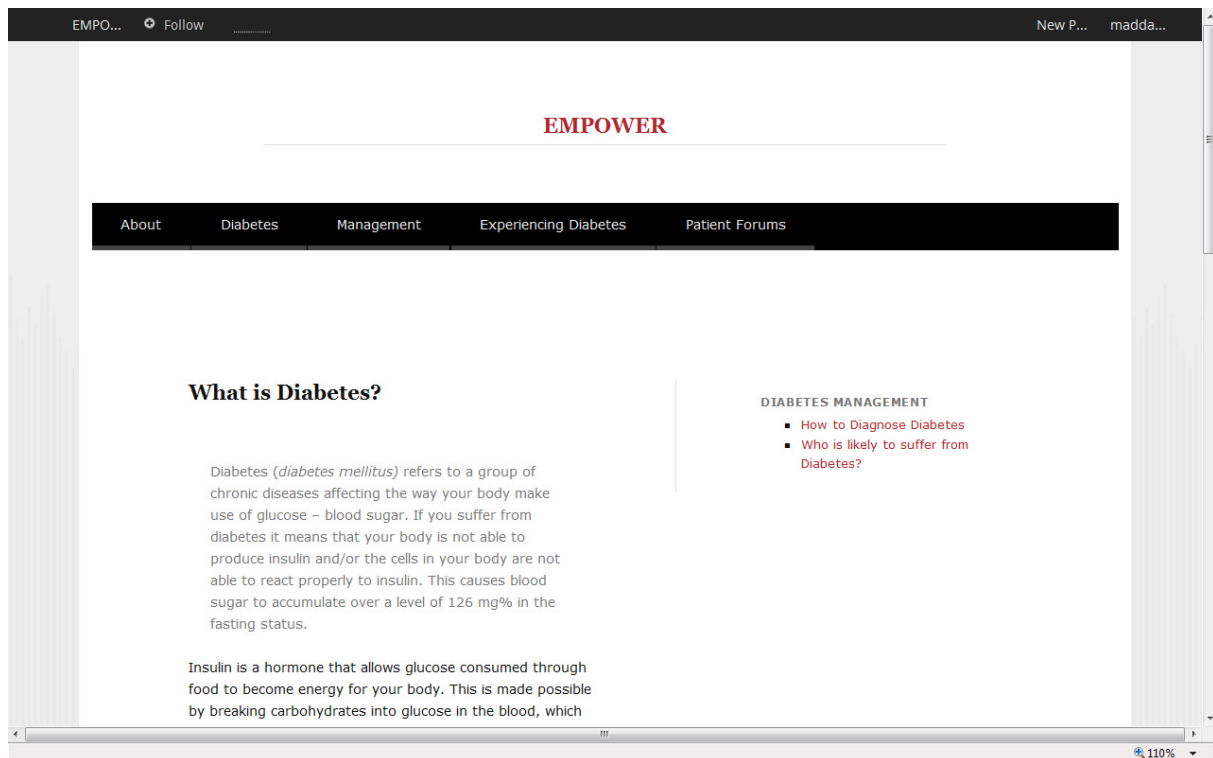


Figure 7: First page of the Diabetes Information chapter: What is diabetes? On the right Diabetes Management links

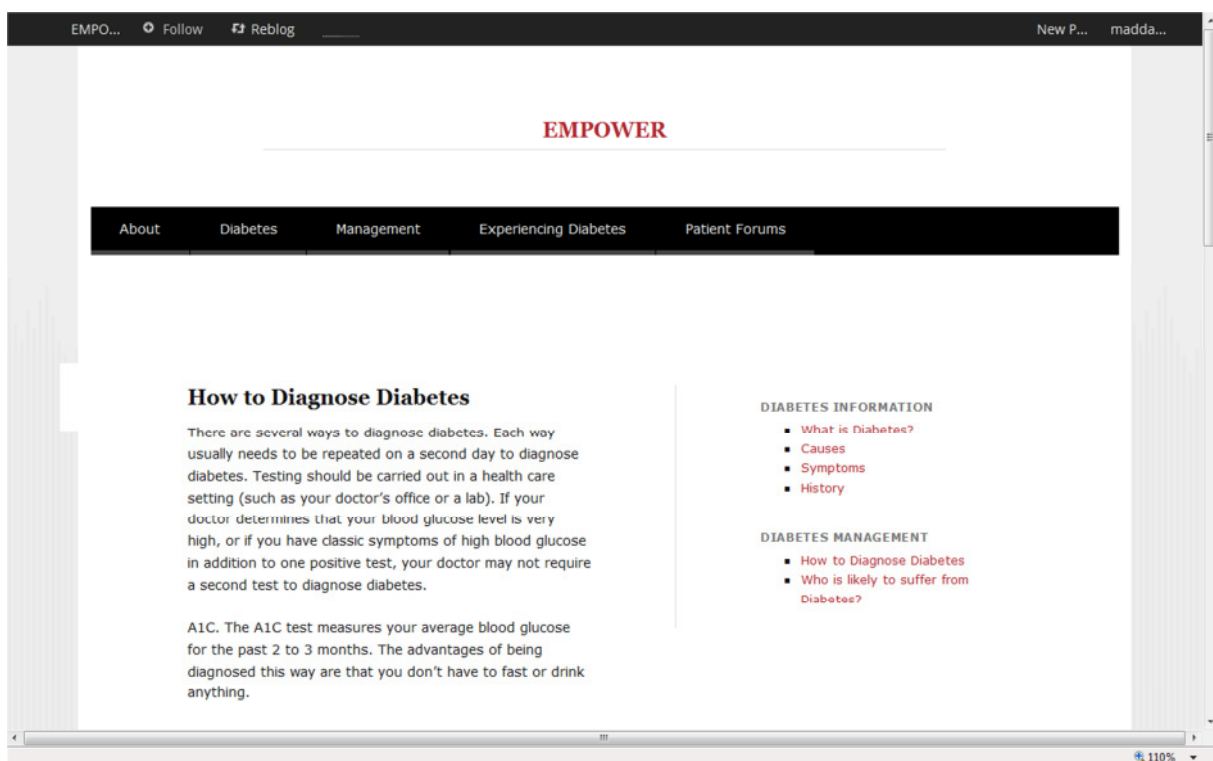


Figure 8: First page of the Diabetes Management chapter: How to diagnose diabetes. On the right Diabetes Information and Diabetes Management links

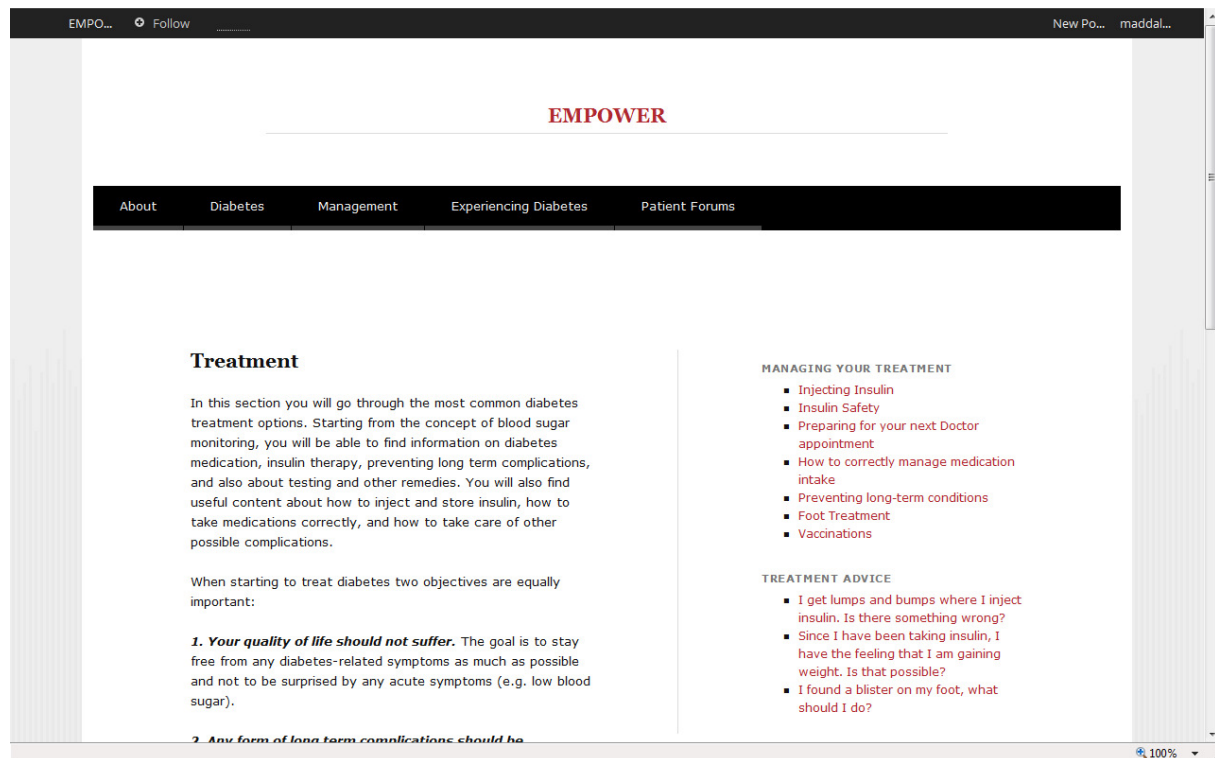


Figure 9: First page of the Treatment Information chapter. On the right Treatment Management and Treatment Advice links

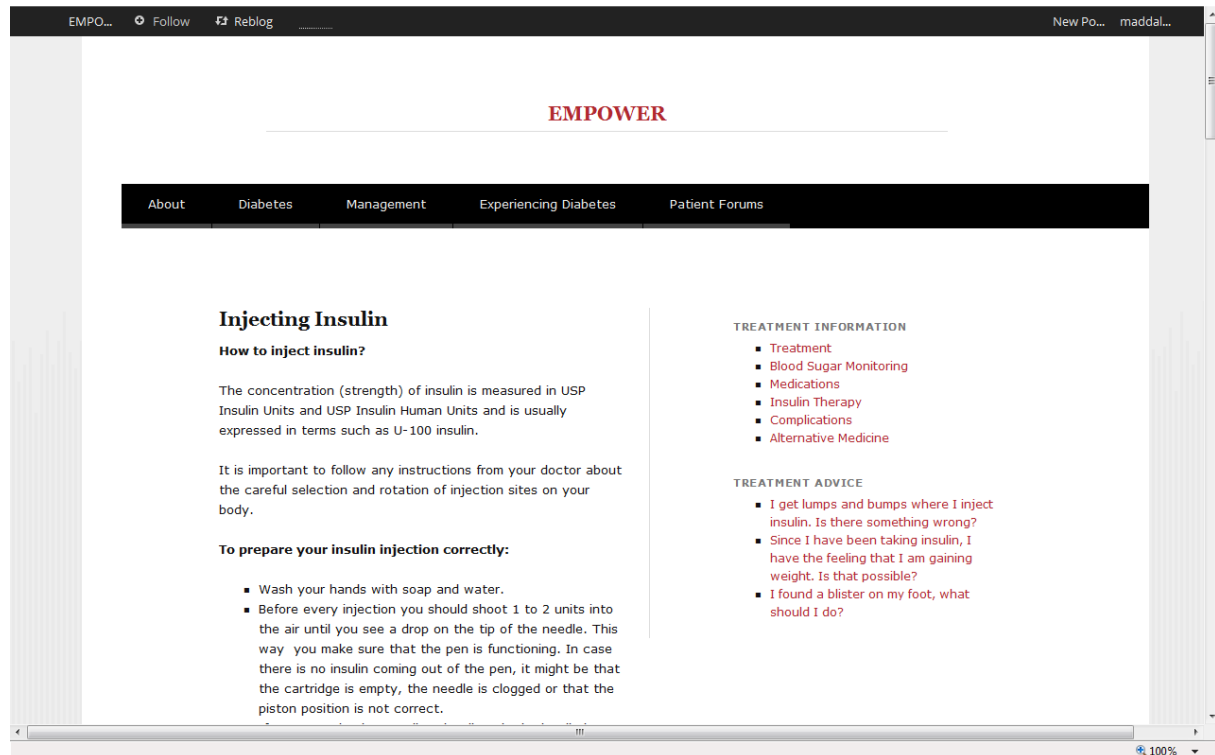


Figure 10: First page of the Treatment Management chapter. On the right Treatment Information and Treatment Advice links

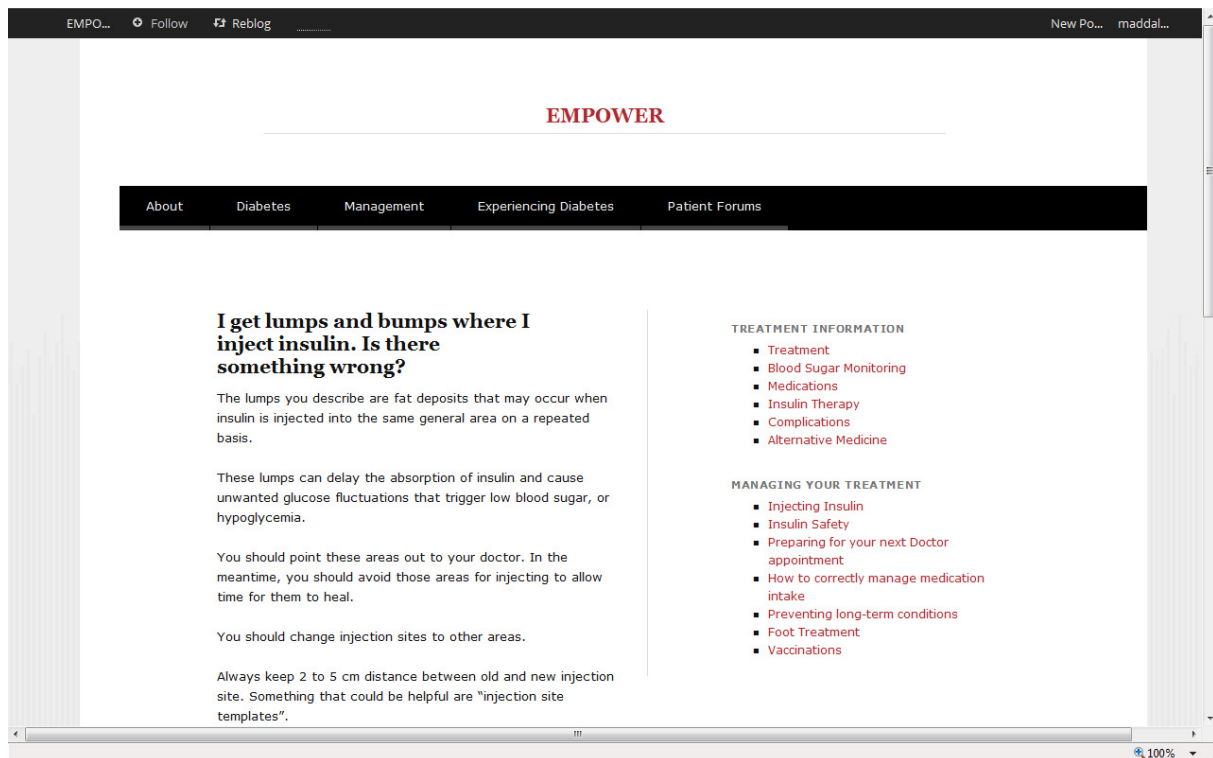


Figure 11: First piece of Treatment Advice. On the right Treatment Information and Treatment Management links.

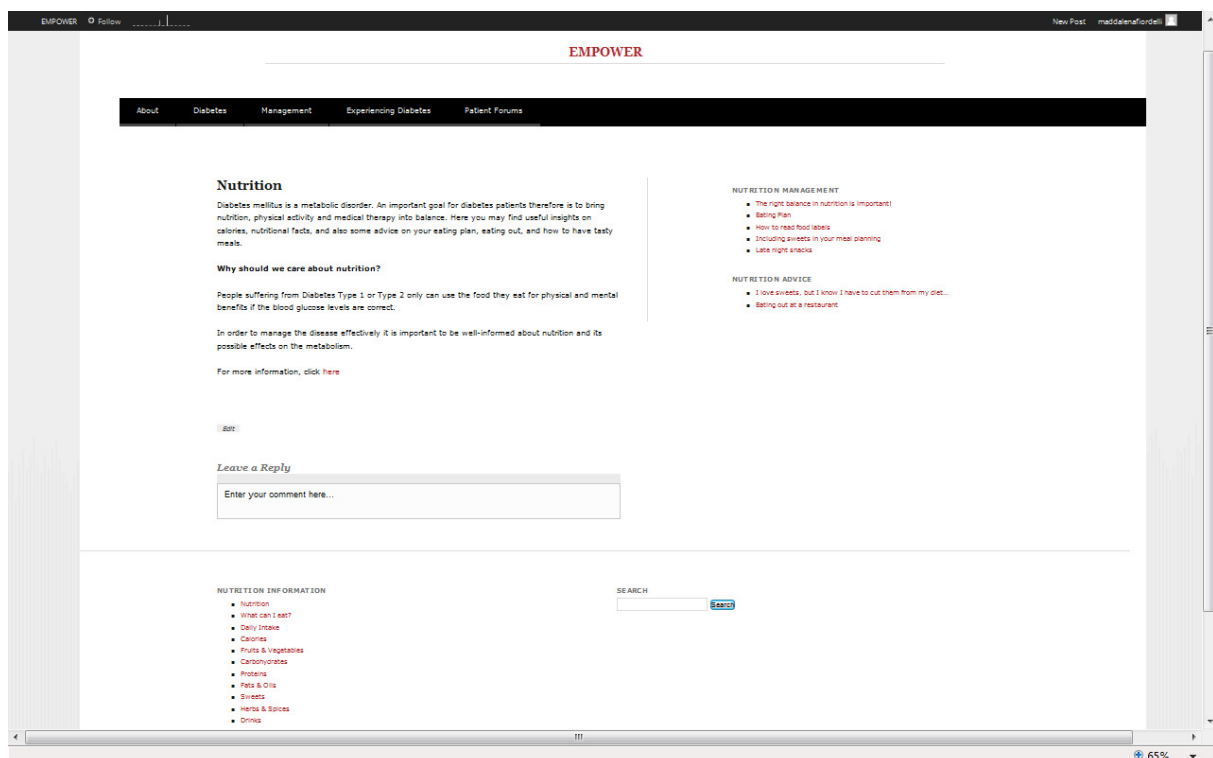


Figure 12: Overview of Nutrition Information Chapter. On the right Nutrition Management and Nutrition Advice links, below Nutrition Information Menu.

5.2 German Translation

<http://empowerpatientde.wordpress.com>

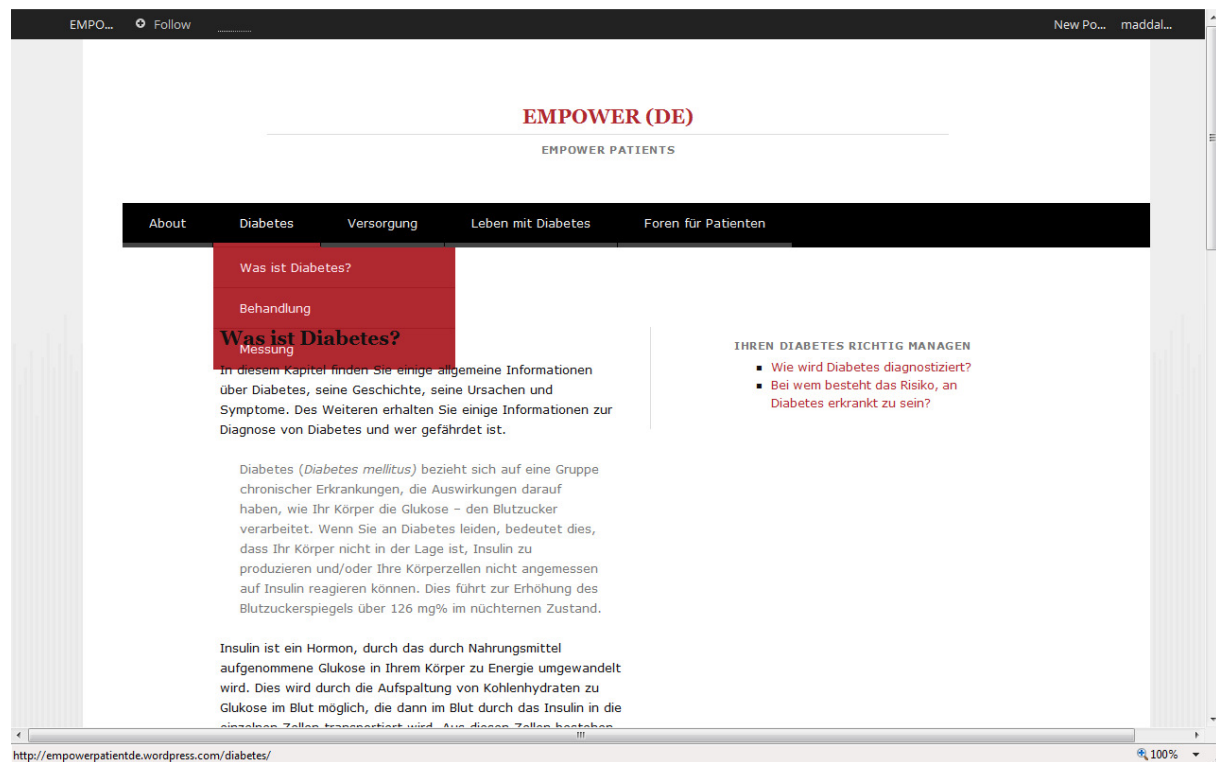


Figure 13: Diabetes submenu with the three information chapters: Diabetes, Treatment, Measurement

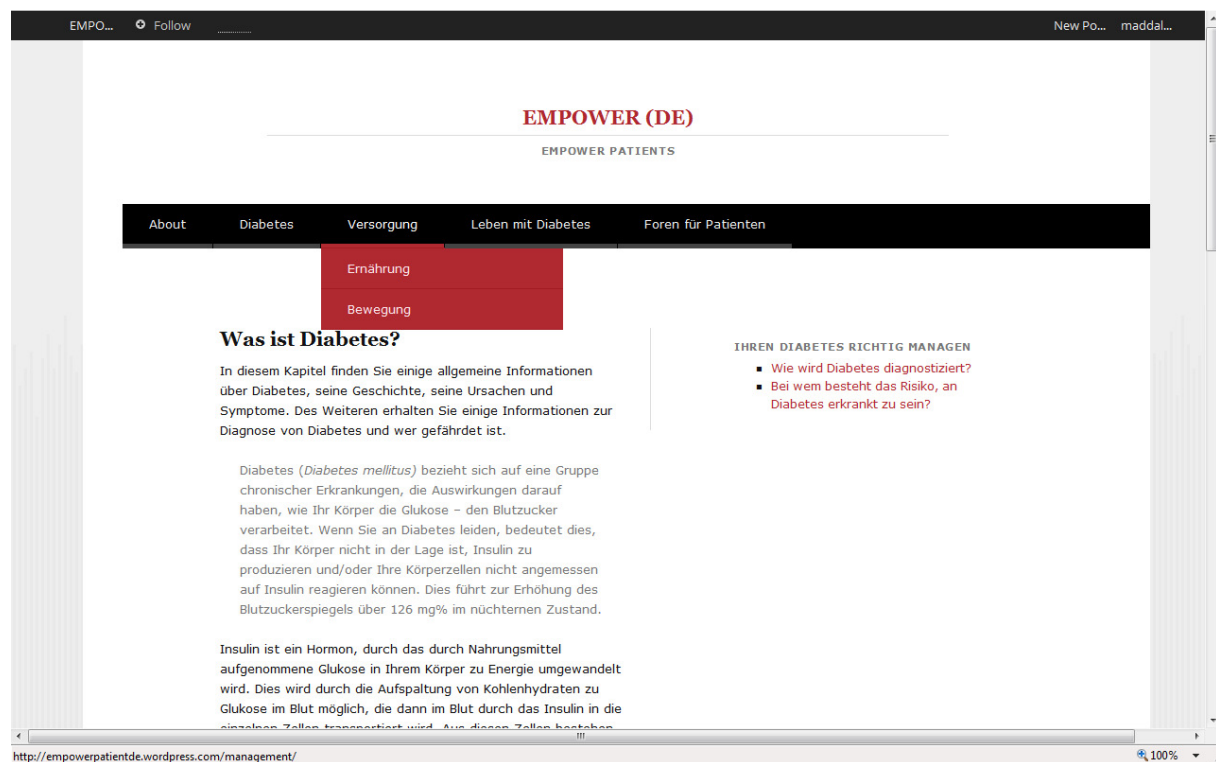


Figure 14: Management submenu with the two information chapters: Nutrition, Exercise

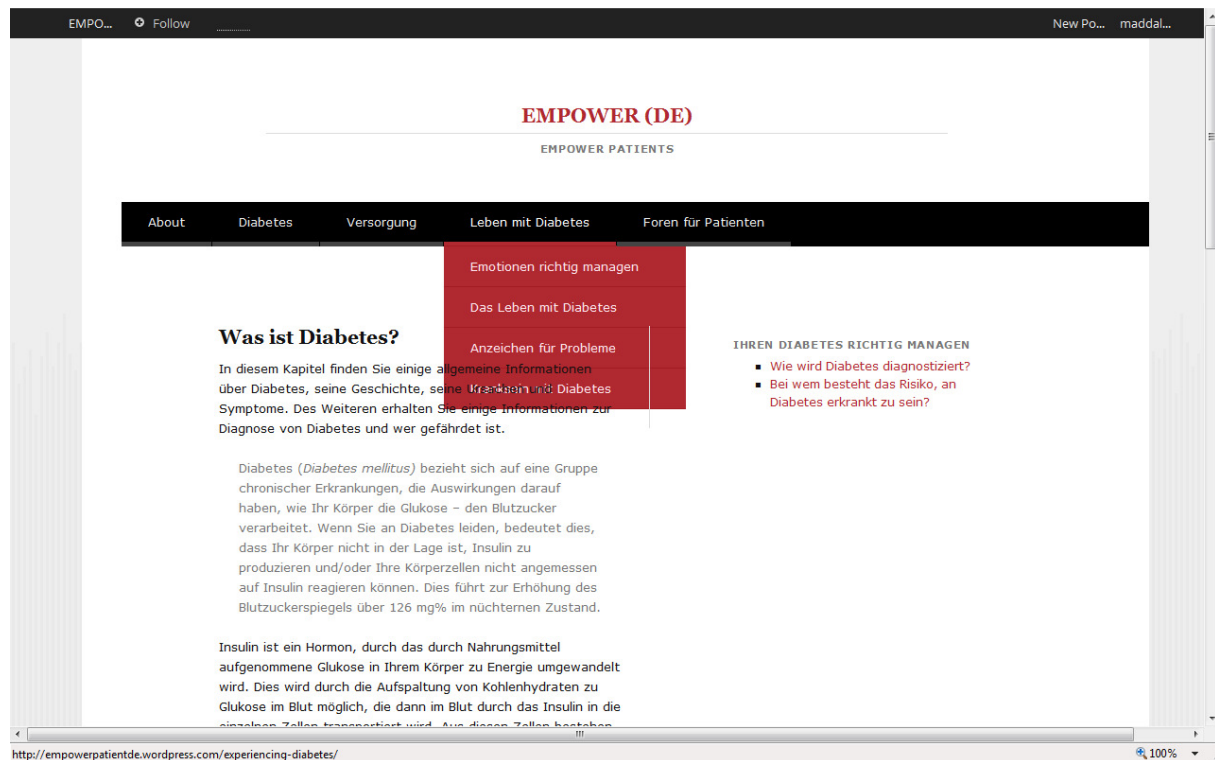


Figure 15: Experiencing diabetes submenu with the four information chapters: Emotions management, Daily life with Diabetes, Signs of Trouble, Being sick with Diabetes

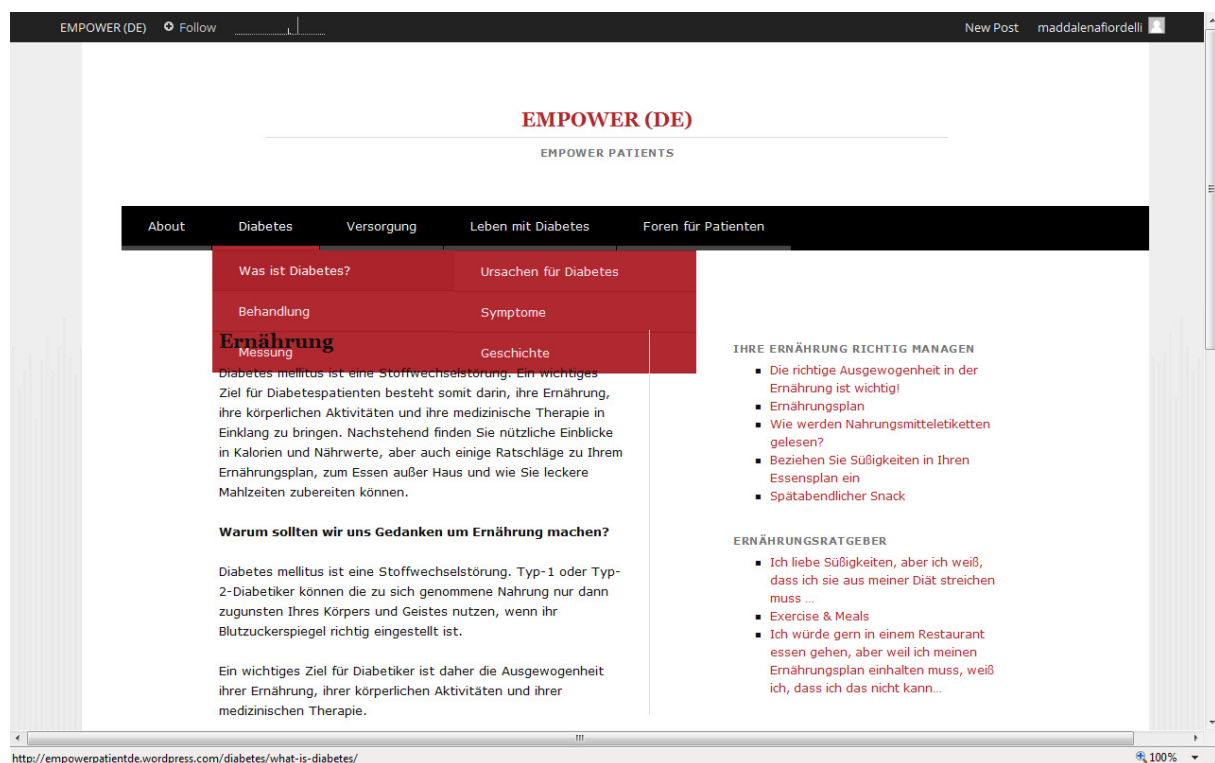


Figure 16: Submenu of the Diabetes Information chapter: Causes, Symptoms, History

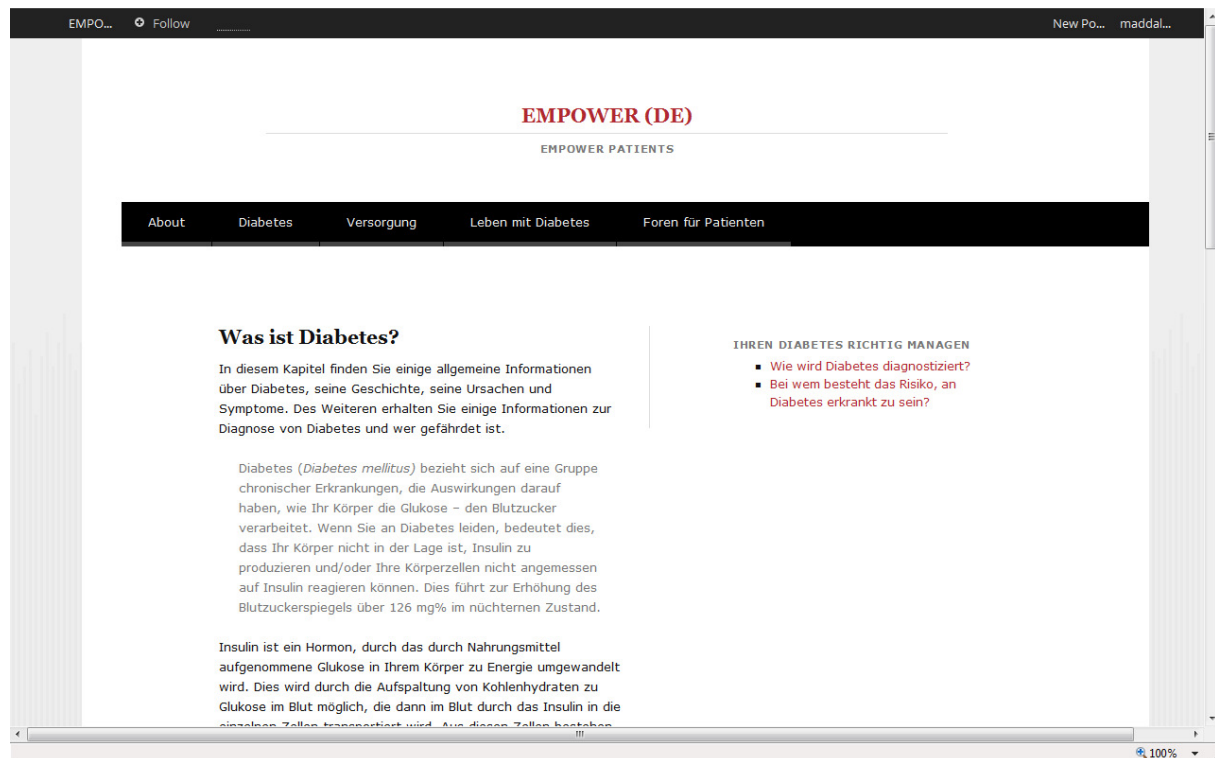


Figure 17: First page of the Diabetes Information chapter: what is diabetes? On the right Diabetes Management links

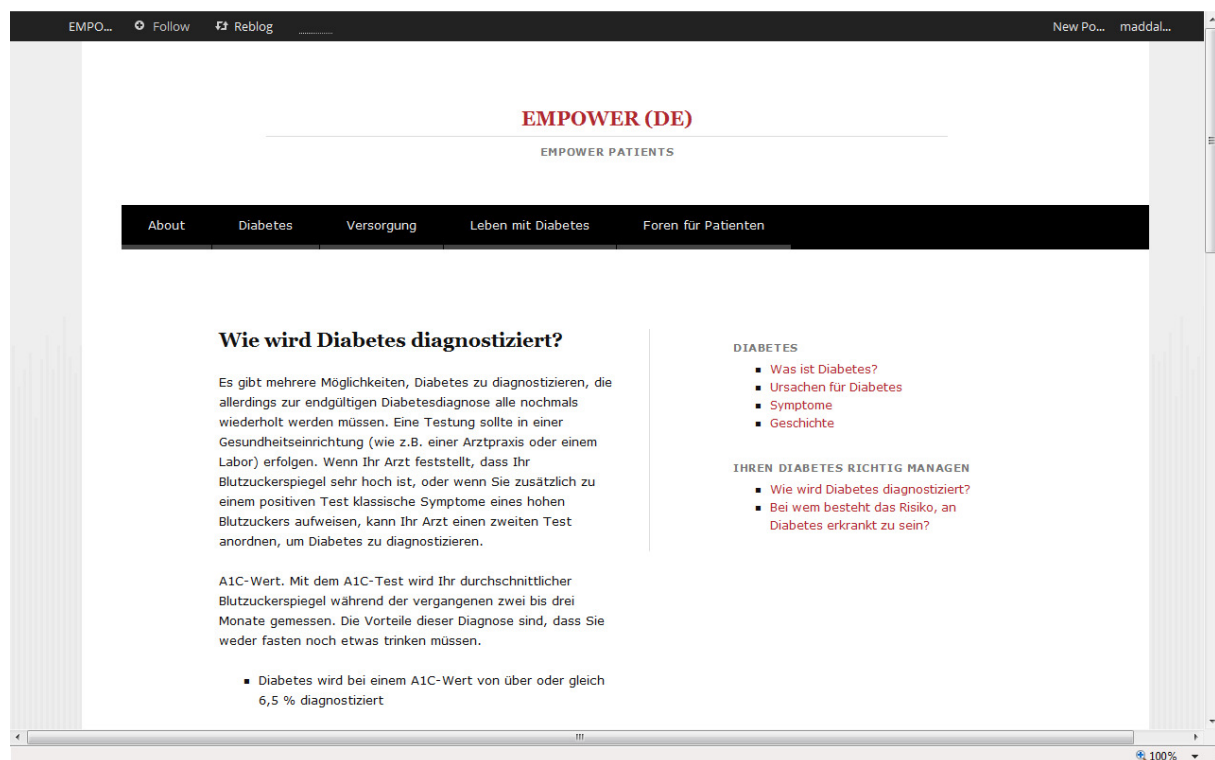


Figure 18: First page of the Diabetes Management chapter: How to diagnose diabetes. On the right Diabetes Information and Diabetes Management links

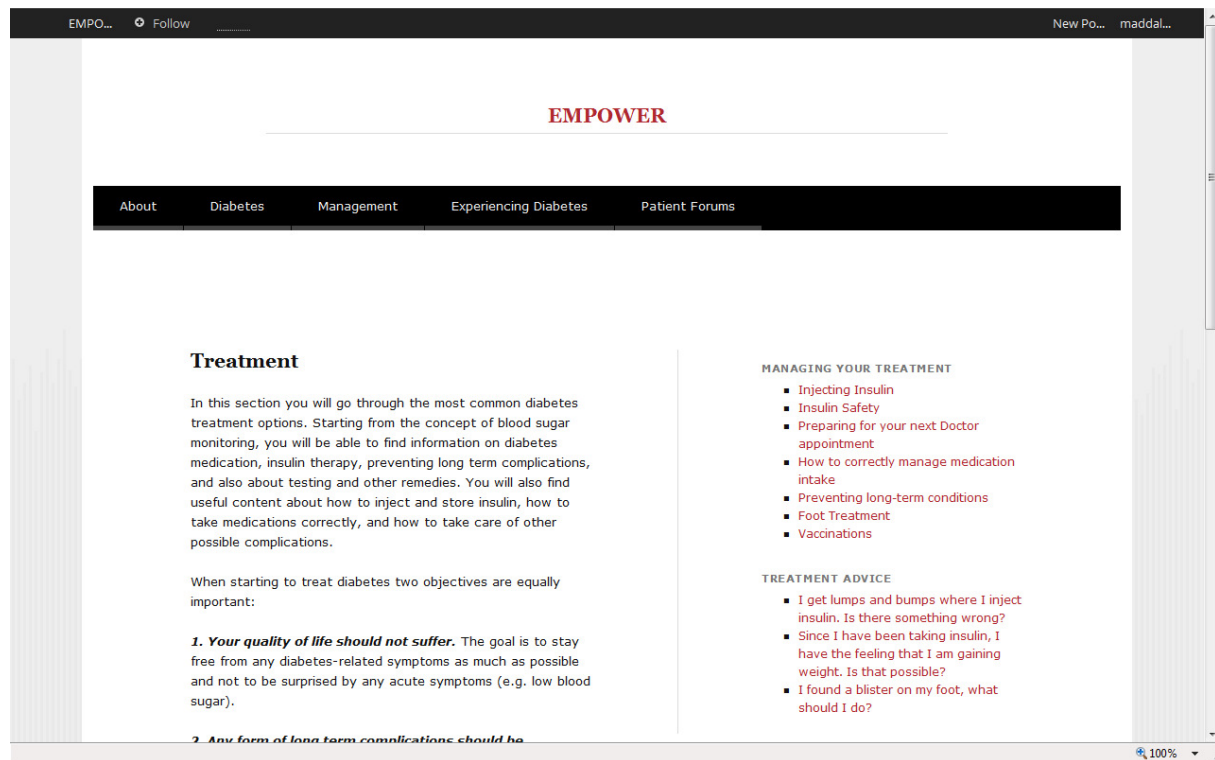


Figure 19: First page of the Treatment Information chapter. On the right Treatment Management and Treatment Advice links

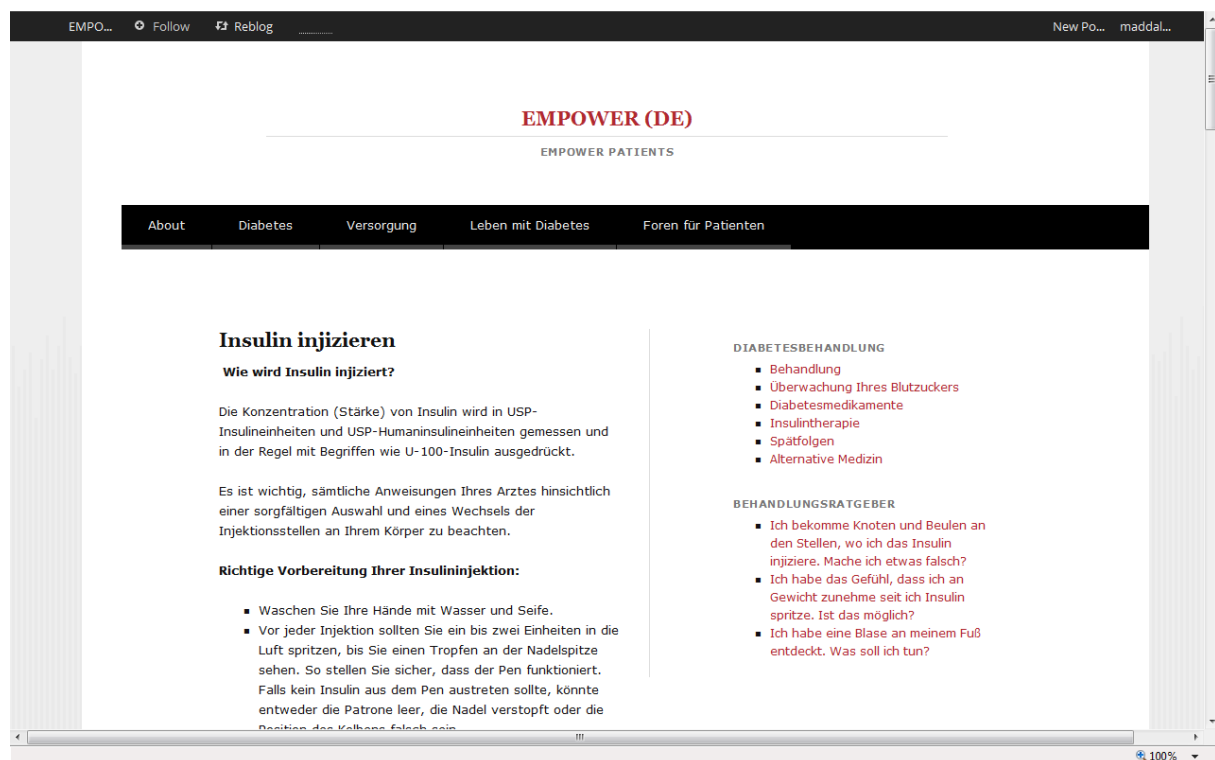


Figure 20: First page of the Treatment Management chapter. On the right Treatment Information and Treatment Advice links

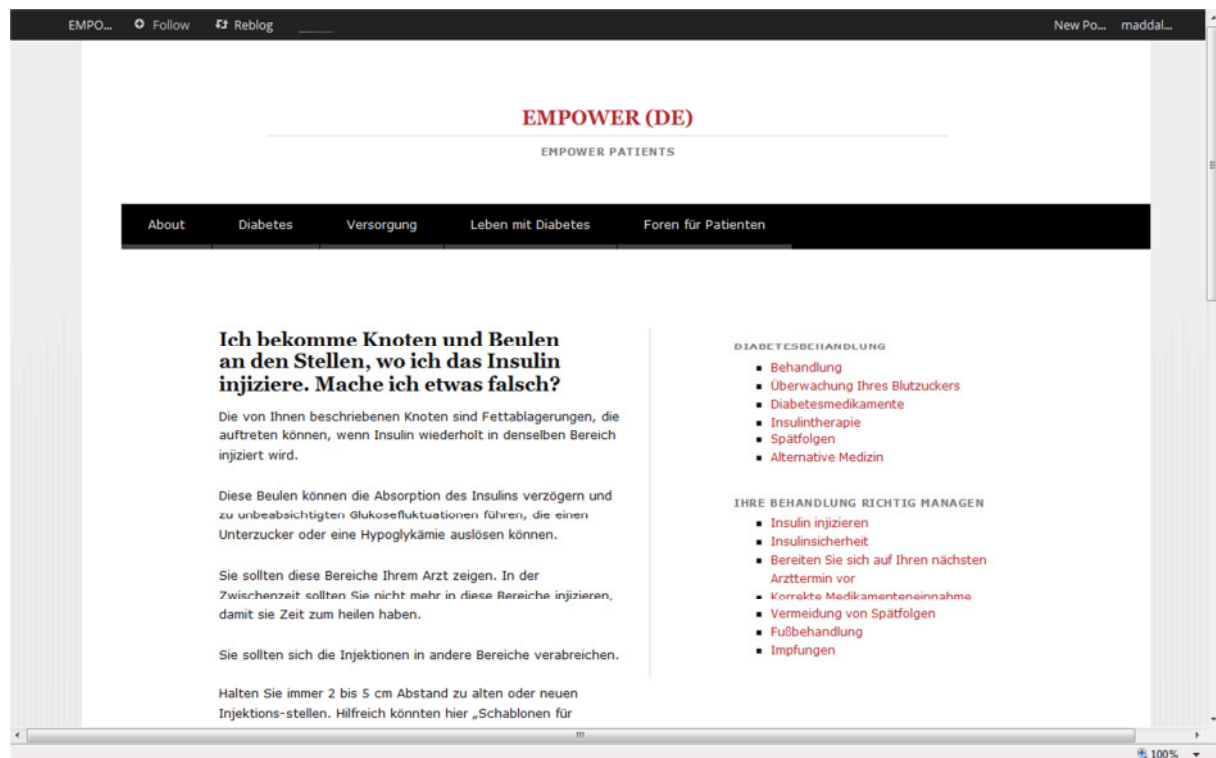


Figure 21: First piece of Treatment Advice. On the right Treatment Information and Treatment Management links.

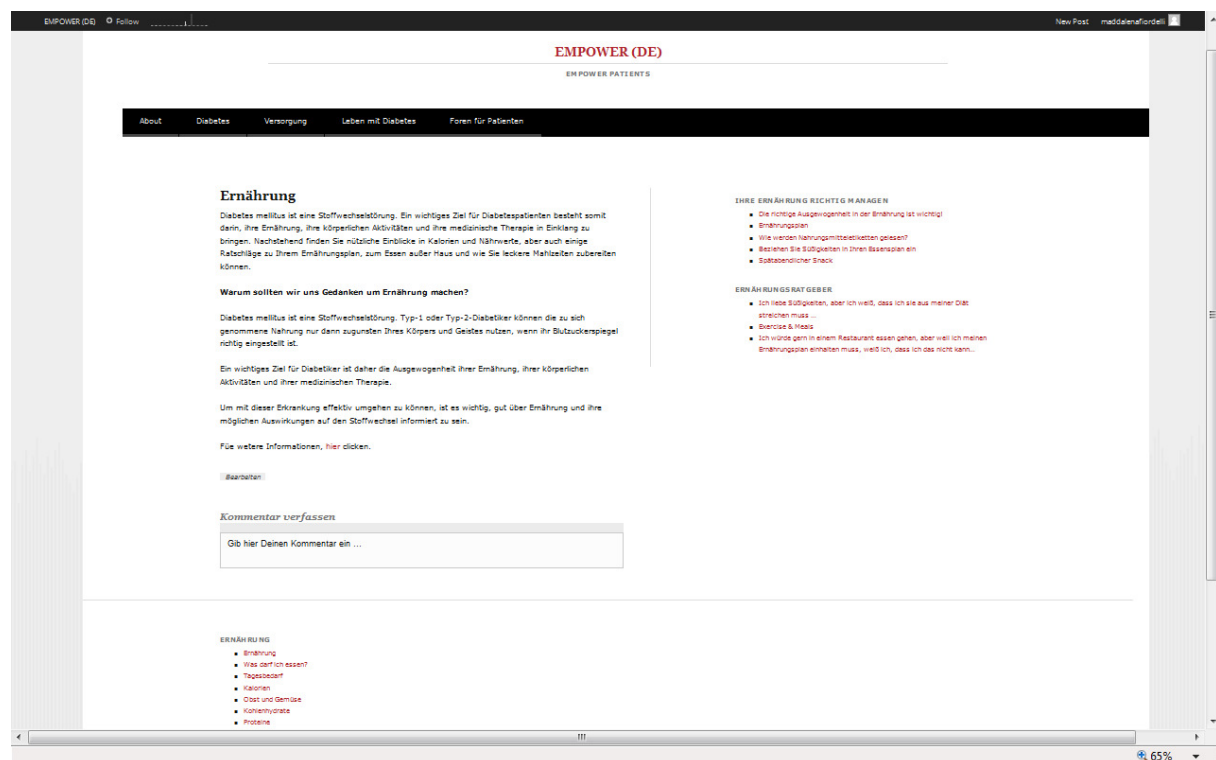


Figure 22: Overview of Nutrition Information Chapter. On the right Nutrition Management and Nutrition Advice links, below Nutrition Information Menu

5.3 Turkish Translation

<http://empowerpatienttr.wordpress.com>

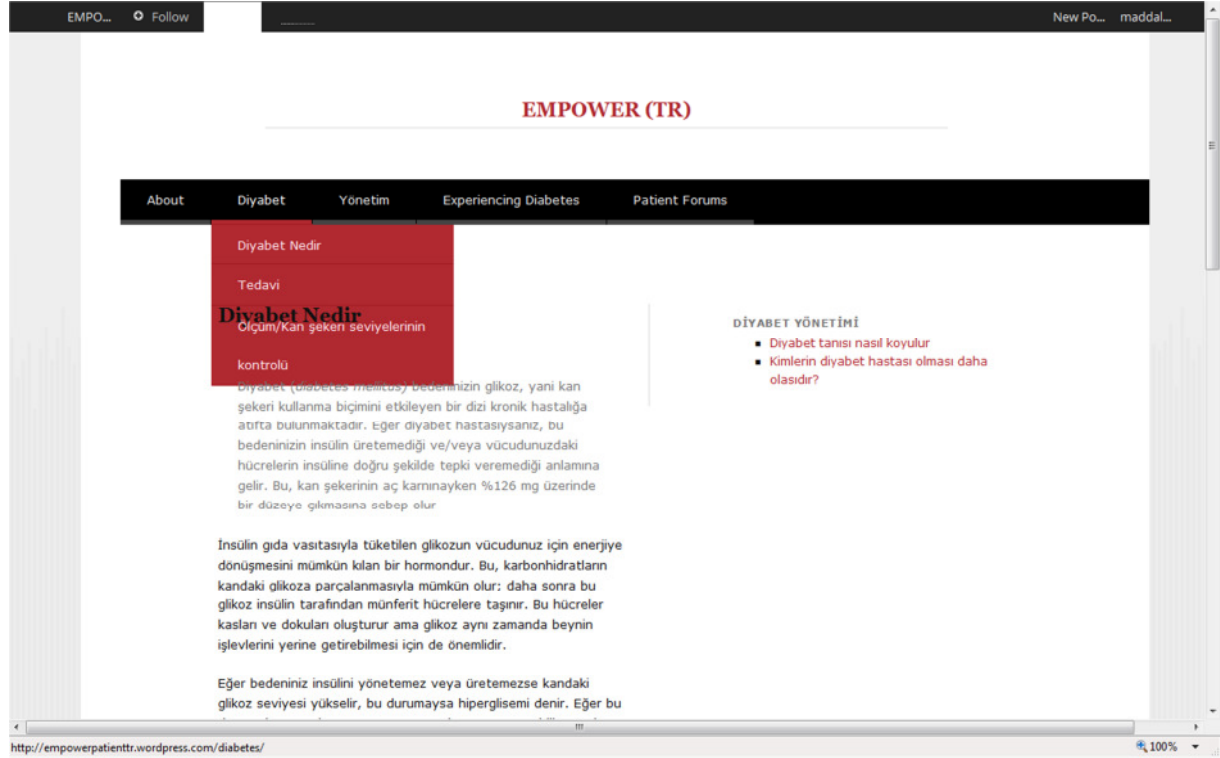


Figure 23: Diabetes submenu with the three information chapters: Diabetes, Treatment, Measurement

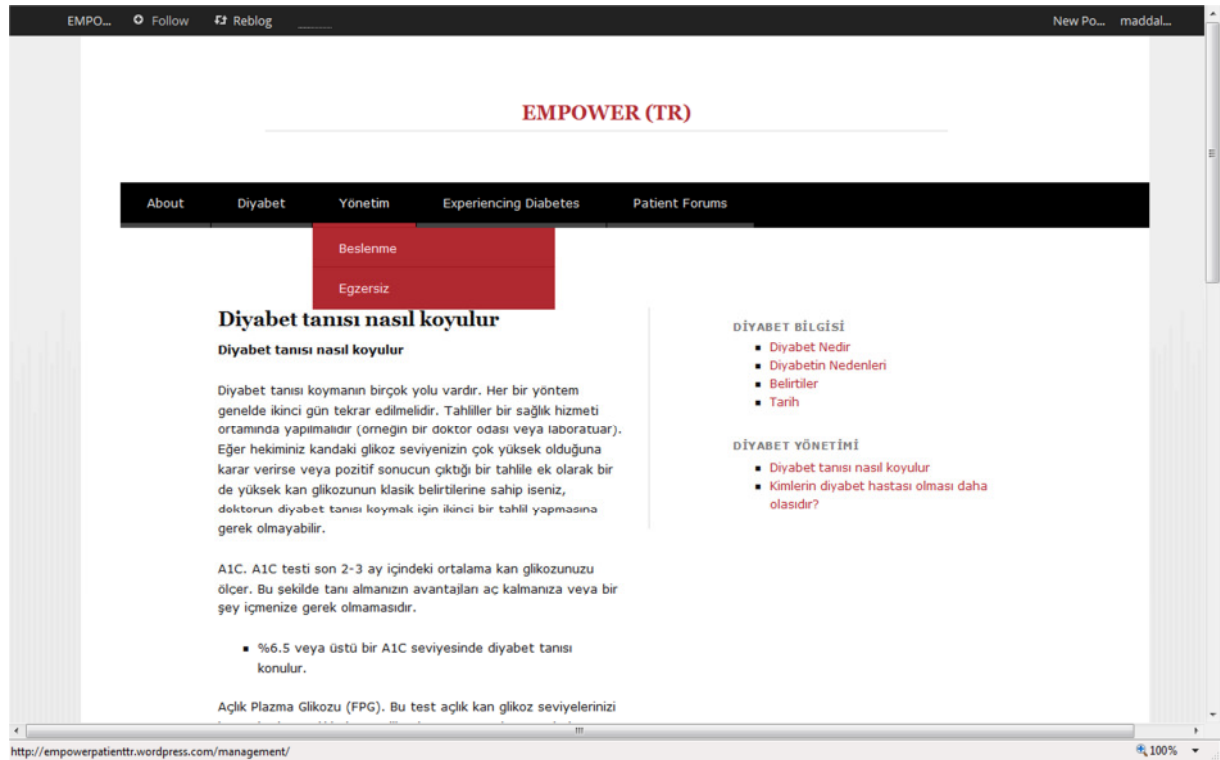


Figure 24: Management submenu with the two information chapters: Nutrition, Exercise

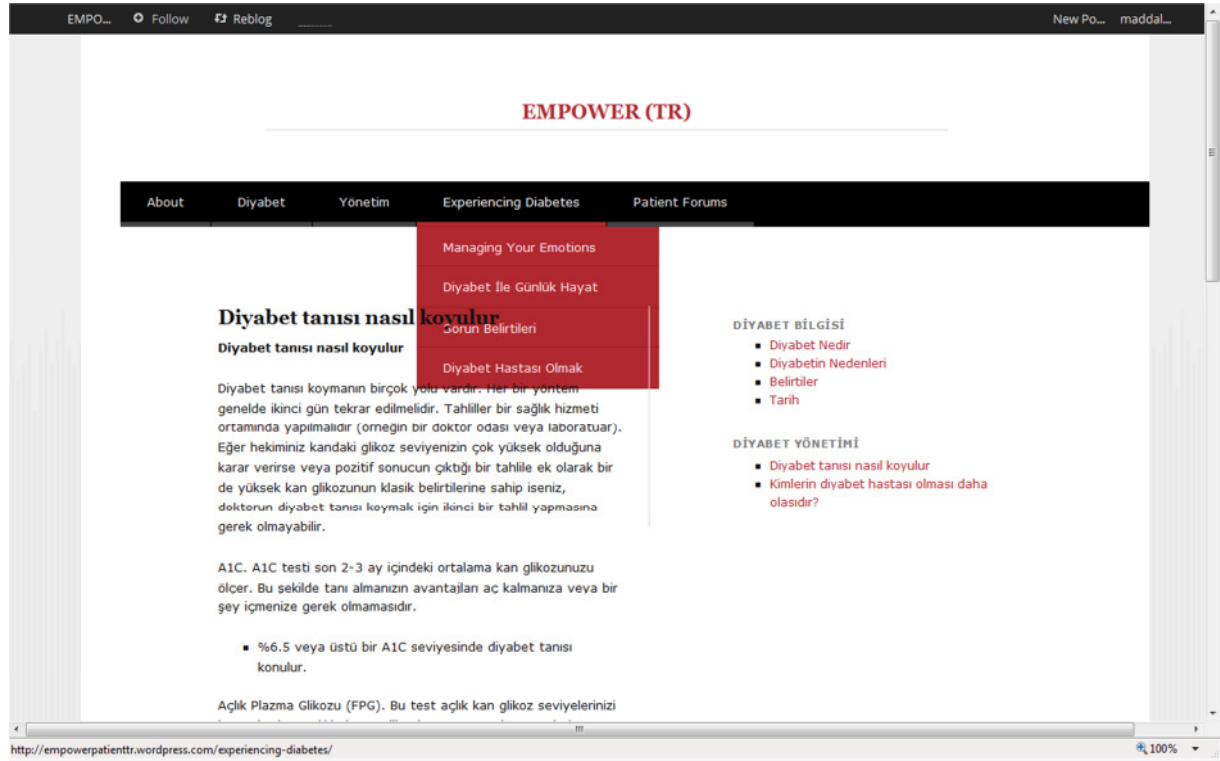


Figure 25: Experiencing diabetes submenu with the four information chapters: Emotions management, Daily life with Diabetes, Signs of Trouble, Being sick with Diabetes

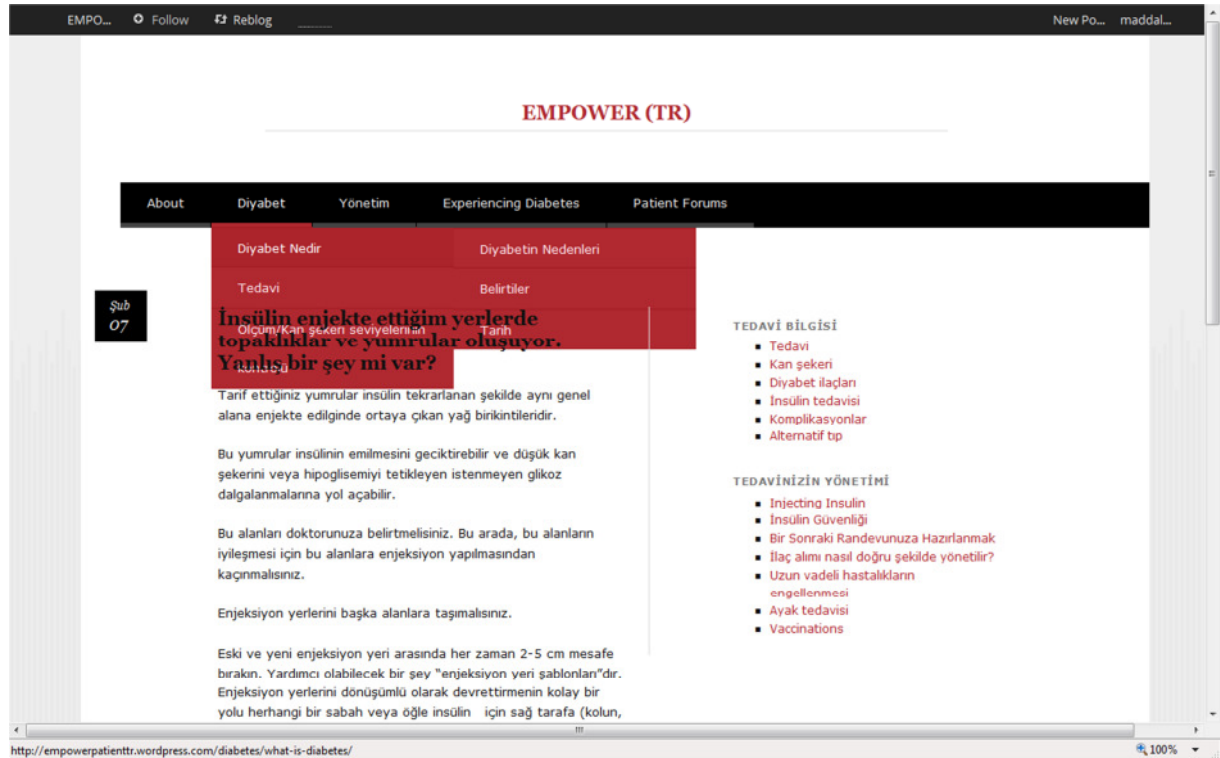


Figure 26: Submenu of the Diabetes Information chapter: Causes, Symptoms, History

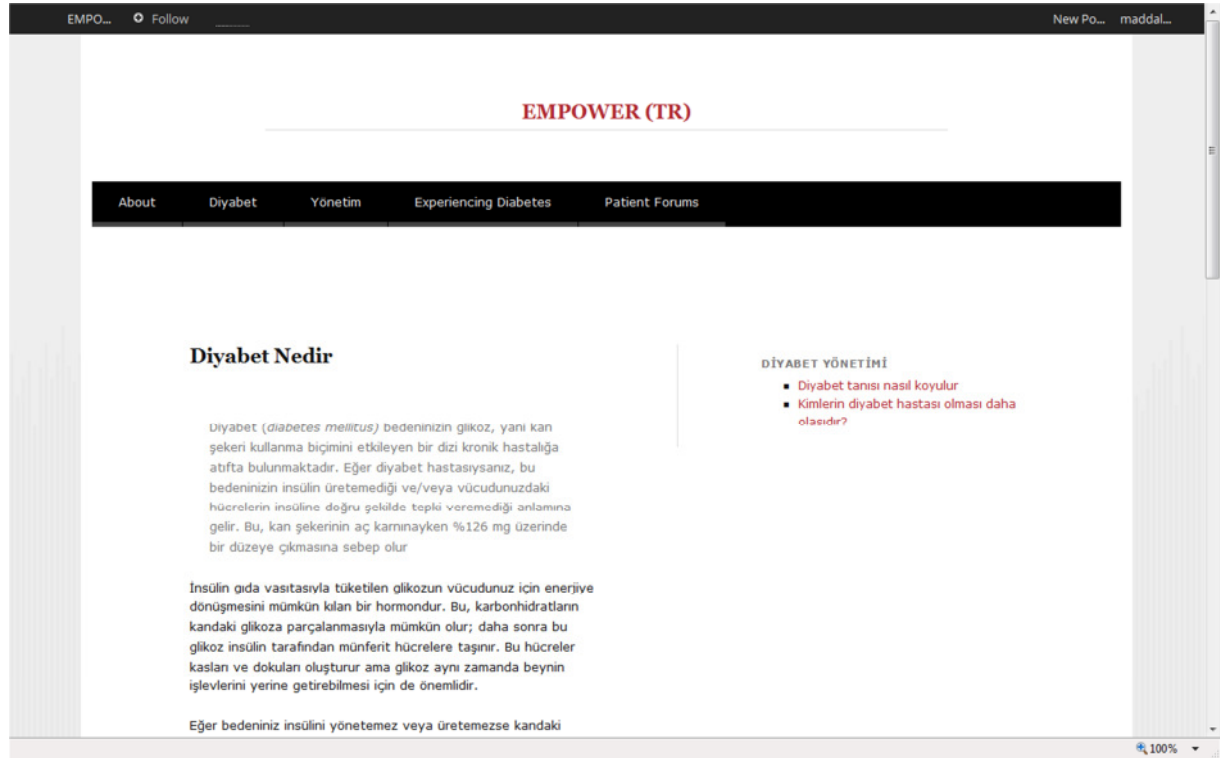


Figure 27: First page of the Diabetes Information chapter: what is diabetes? On the right Diabetes Management links

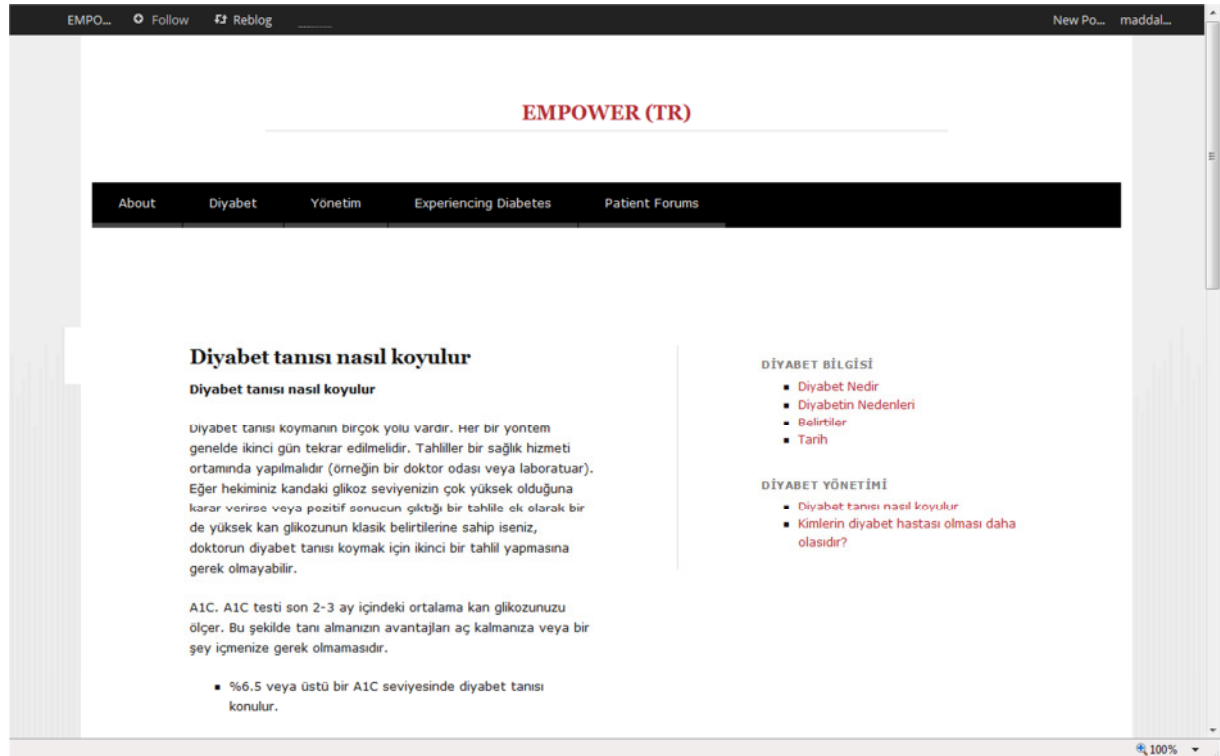


Figure 28: First page of the Diabetes Management chapter: How to diagnose diabetes. On the right Diabetes Information and Diabetes Management links

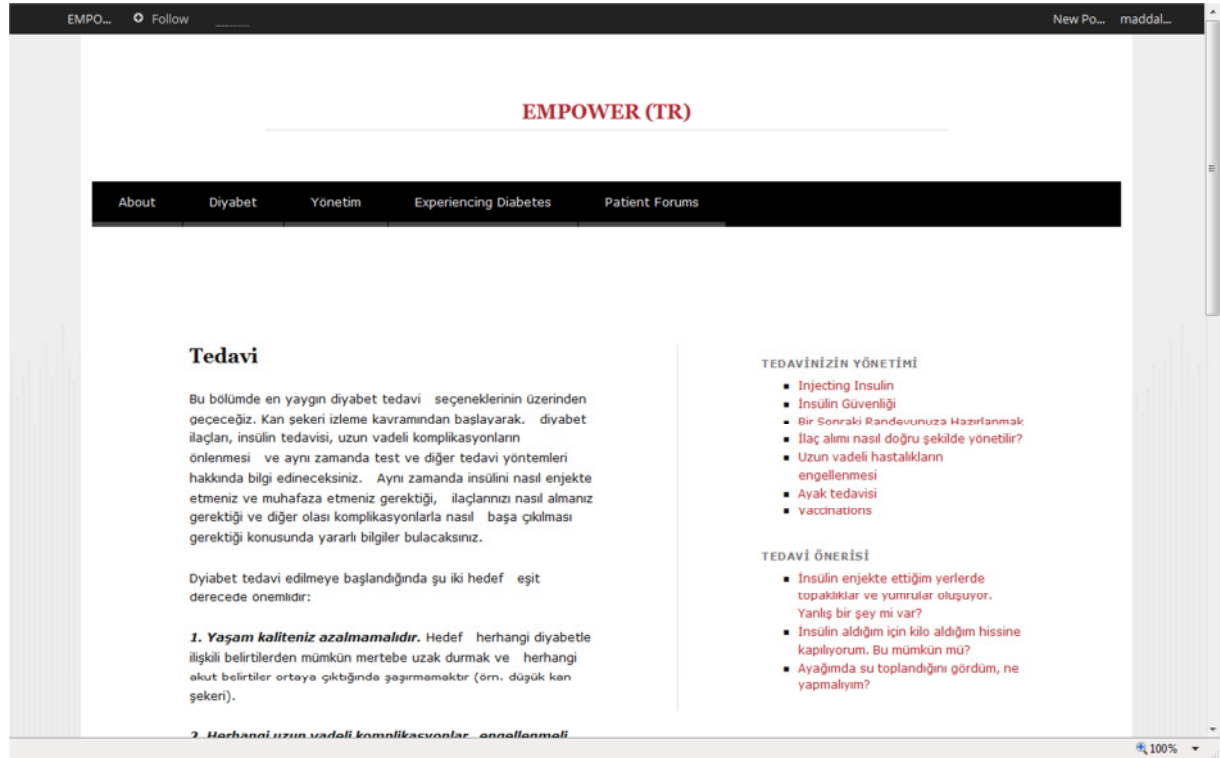


Figure 29: First page of the Treatment Information chapter. On the right Treatment Management and Treatment Advice links

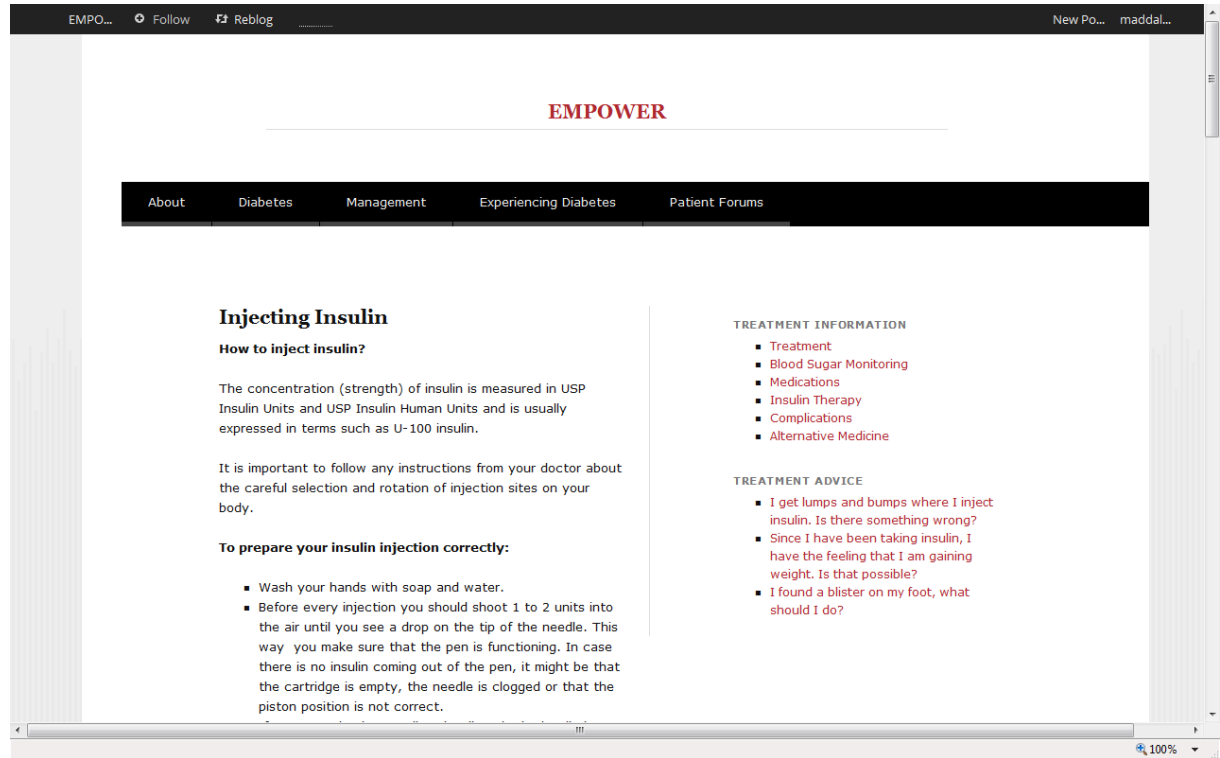


Figure 30: First page of the Treatment Management chapter. On the right Treatment Information and Treatment Advice links



Figure 31: First piece of Treatment Advice. On the right Treatment Information and Treatment Management links.

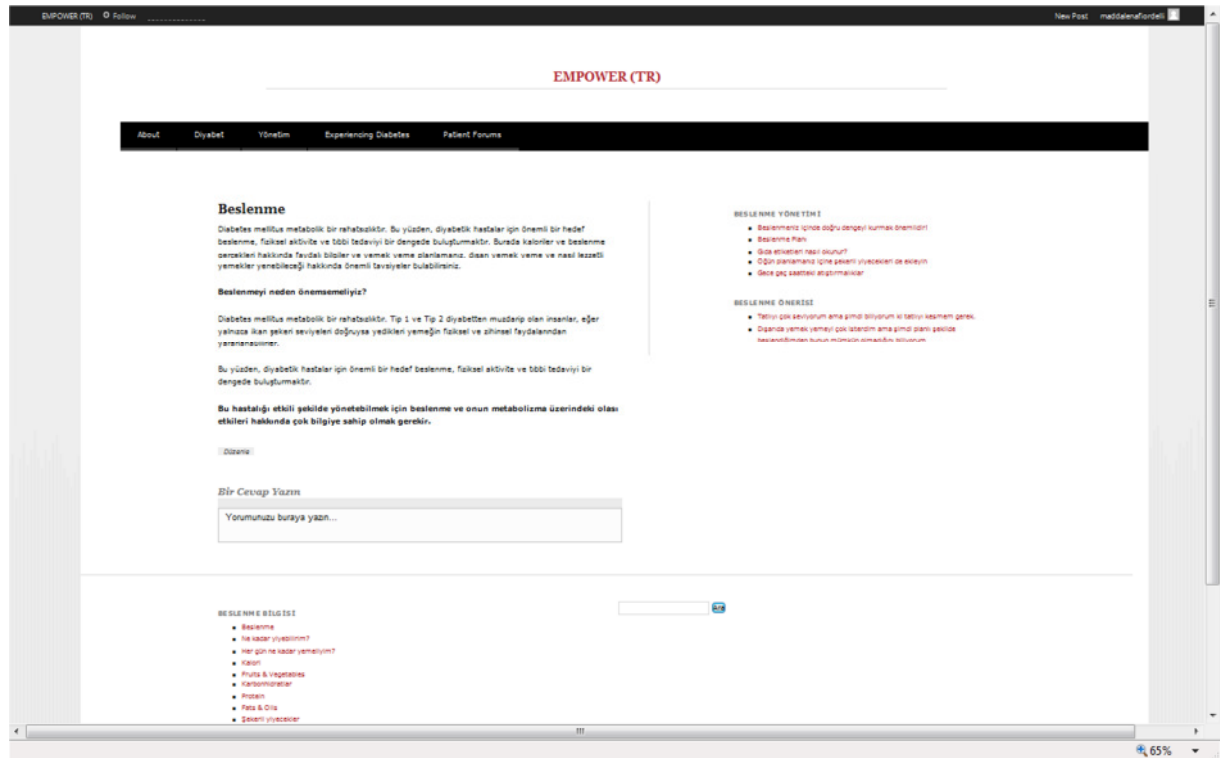


Figure 32: Overview of Nutrition Information Chapter. On the right Nutrition Management and Nutrition Advice links, below Nutrition Information Menu.

6 Validation of Patient Information Material

Patient information material will be validated during phase I of the validation. Diabetes patients (5-10) and physicians (2-3) will be recruited for each of the Pilot Applications in Ingolstadt and Ankara. The main goals of the evaluation will be to receive a first feedback on EMPOWER features, after participants having interacted with the prototype. Participants' feedback will be collected mainly in terms of: Usability, Usefulness/Perceived Usefulness, and Acceptance and Barriers. Among the modules assessed by the patients there will be the Patient Information Material. The results will be integrated in the software developments for the final prototype.