



Quality of Care Standard supports healthcare practitioners and patients alike

Quite often, neither healthcare practitioners nor the patients know enough about adrenal gland disorders and their treatment. This can lead to serious health risks. The Quality of Care Standard for Adrenal Disorders is intended to help change this situation. Patients played a leading role in drawing up the document that was officially listed in the Register of the Dutch National Health Care Institute in September 2018.

The process of developing the Quality of Care Standard for Adrenal Disorders and the associated aids took over three years. Patients, informal carers, doctors and nurses reviewed each new version and added their comments. This was important, because they are the people who will ultimately be using the Quality of Care Standard to improve the health and life of patients with an adrenal disorder. The document explains to health practitioners and patients what 'good care' for someone with an adrenal disorder means. It also helps patients find the best way to cope with their illness and its consequences. Various aids have been developed to help healthcare practitioners and patients share in the decision taking about treatment on equal terms. This patient orientation makes the Quality of Care Standard for Adrenal Disorders a pioneering achievement in the domain of healthcare.

Work to be done

The true involvement of, and attention for the patient is firmly embedded in AdrenalNET, the 'consortium' that initiated the development of the standard. This knowledge consortium includes the endocrinology departments of the Dutch university hospitals and teaching hospitals, the Dutch Adrenal Society (Bijniervereniging) NVACP and the Dutch Pituitary Society (Nederlandse Hypofyse Stichting).

The results of a baseline survey - carried out in 2015 among patients, doctors and informal carers - made it clear that there was work to be done. "Because most healthcare practitioners are hardly ever confronted with adrenal disorders, it can take as long as twenty years before patients are correctly diagnosed", says AdrenalNET coordinator Johan Beun who himself has an adrenal disorder. "And that also means that you may have to wait for years before you see the right doctor and get appropriate treatment. Because of their lack of knowledge and skills, patients and healthcare practitioners were often unable to take the right action in emergency situations. Patients were either unable or too afraid to administer an injection if their tablets weren't 'working'. And even in hospitals there was not always someone available who had the right knowledge. Patients

Listing in the Register

Improving the quality of healthcare is an important aspect of the remit of the Dutch National Health Care Institute. That is why this government agency encourages doctors, patients and health insurers to join forces and describe what they think comprises 'good healthcare'. These descriptions of 'good healthcare' are then formulated in a quality of care standard. Quality of care standards have to fulfil strict criteria if they are to be listed in the National Health Care Institute's register. An important criteria is that healthcare practitioners, patients and healthcare insurers have to have collaborated fully in its contents.

But that proved to be a stumbling block with regard to the Quality of Care Standard for Adrenal Disorders. The Association of Healthcare Insurers in the Netherlands was unable to make anyone available to work on this project for rare disorders. It is estimated that the number of adrenal patients in the Netherlands is between 5,000 and 7,000 (pop: 17 mln). The insurers were, however, eager to endorse the contents of the document. The National Health Care Institute therefore decided to accept the Quality of Care Standard for Adrenal Disorders for listing in the Register. This is a public register and available for those who can read Dutch.



sometimes waited in the emergency room for a long time without being given the correct treatment. A risky situation."

With the aid of the Quality of Care Standard for Adrenal Disorders, AdrenalNET aims to improve the diagnostic process and the treatment, health and quality of life for patients. The document is intended to help avoid future recurrences of the problems that came to light as a result of the baseline survey.

Infographics, mini-documentaries and animated clips

The Quality of Care Standard for Adrenal Disorders is impressive for several reasons. The content of the document is significant, covering 200 pages. Many parties (see inset) and people have put a lot of time and effort into the project over the course of the three year development period. There were also financial challenges to be overcome. "In the beginning we rather underestimated what would be involved in drawing up something like this", Johan admits. "But thanks to everyone's belief in the project, and their hard work, we managed to get it done. A special word of thanks has to go to AdrenalNET's secretary, Alida Noordzij, endocrinologist Lisanne Smans and Ad Hermus, professor of endocrinology and chairman of AdrenalNET. They were sometimes quite literally working day and night on the contents of the Quality of Care Standard."

The most impressive aspect of the document is therefore its contents. The Quality of Care Standard consists of five modules, each of them focussing on a single adrenal disorder. Each module contains specific information which is important for the care and counselling of patients with that particular disorder. Six general modules cover subjects such as improving knowledge about adrenal disorders, how healthcare is organised, diagnostics and customised medication. Another section looks at the participation of adrenal patients in the labour market, a domain in which patients often find themselves at a disadvantage. There are also special patient versions of all these modules. Attention is also given to the translation of the Quality of Care Standard in practical terms. For example, AdrenalNET has produced infographics, mini-documentaries and animated clips which present information about the various disorders in a way that everyone can understand. E-learning modules have also been developed so that nursing staff can improve their knowledge of adrenal disorders.

The Quality of Care Standard for Adrenal Disorders in the Netherlands came about thanks to the cooperation and support of:

- BijnierNET / AdrenalNET;
- the National Working Group of Endocrine Nurses (LWEV);
- the Dutch Association for Internal Medicine (NIV);
- the Dutch Endocrine Society (NVE);
- the Royal Netherlands Society for the Advancement of Pharmacology (KNMP);
- the Dutch Adrenal Society NVACP;
- the Dutch Association for Clinical Chemistry & Laboratory Medicine (NVKC);
- the Dutch Association for Urology (NvU);
- the Dutch Association of Surgeons (NVvH);
- the Dutch Association of Neurosurgeons (NVvN);
- the Dutch Pituitary Society.

**Continual revision**

According to Johan, listing in the Register is just the beginning. "If patients and healthcare practitioners do not use the standard, we will have done all that work for nothing. So we are organising regional meetings in different parts of the country to introduce the standard to both patients and healthcare practitioners. And it doesn't stop with simply providing information: we also try to make concrete arrangements. About how we are going to ensure that patients receive instruction about how to administer an emergency injection, for example. We encourage hospitals to follow the guidelines given in the Quality of Care Standard. The fact that the standard has been included in the National Health Care Institute's register certainly helps in that respect, by giving it more authority. After all, it had to fulfil strict criteria and go through an independent review before it could be listed. We are also helping to find ways in which university and regional hospitals can support each other to provide the best care for patients, 24 hours a day and 7 days a week. Ultimately we want to be able to reveal which hospitals are working according to the standard and which aren't. Patients will then be able to make a better choice of which hospital they want to go to for treatment."

Johan insists that the contents of the Quality of Care Standard for Adrenal Disorders are not carved in stone. "Patient associations told us that the patient versions of the modules were not completely appropriate for the information needs of their members. So we rewrote some of the texts and included a lot of supporting illustrations, and we will continue to revise the standard to satisfy new needs and requirements."

Further information about the Quality of Care Standard in the Netherlands?

Please contact AdrenalNET at INFO@ADRENALNET.EU

Kwaliteitsstandaard Bijnieraandoeningen

Bijnierschorsinsufficiëntie, AGS, Cushing, primair hyperaldosteronisme, feochromocytoom

Interne ziekten-Endocrien systeem



Kwaliteitsstandaard opgenomen in het Register

Opgenomen in het Register: 04 september 2018

Omschrijving

Bijnierschorsinsufficiëntie, het adrenogenitaal syndroom, het syndroom van Cushing, primair hyperaldosteronisme en feochromocytoom zijn zeldzame aandoeningen van de bijnieren. Er is grote behoefte aan meer bekendheid en kennis bij alle zorgverleners betrokken bij de zorg voor patiënten met een bijnieraandoening teneinde diagnostische vertraging te verminderen, de diagnostiek en behandeling te verbeteren, complicaties en comorbiditeit op de korte en lange termijn te voorkomen en de kwaliteit van leven voor patiënten te verbeteren. De zorg voor patiënten met deze zeldzame aandoeningen van de bijnieren is hoog complex waarbij zorg op maat en een multidisciplinaire aanpak essentieel zijn. In de Kwaliteitsstandaard Bijnieraandoeningen worden de knelpunten, die voortvloeien uit de knelpuntenanalyse onder zorgvragers en zorgverleners, met behulp van uitgangspunten en deelvragen in verschillende ziektespecifieke en generieke (ziekte-overstijgende) modules uitgewerkt.

Actuele versie	Publ. datum	Type
→ Infographics bijnierschorsinsufficiëntie	17-08-16	Overige
→ Infographic syndroom van Cushing	17-08-16	Overige
→ Infographic primair hyperaldosteronisme	17-08-16	Overige
→ Infographic feochromocytoom	17-08-16	Overige

Documenten bij kwaliteitsstandaard	Publ. datum	Type	Grootte
20180404 Patiënteninformatie Bevordering van bekendheid en kennis bijnieraandoeningen (versie 1).pdf	20-04-18	Clëntenversie	272,86 KB
20180404 Patiëntenversie adrenogenitaal syndroom (versie 1).pdf	20-04-18	Clëntenversie	392,78 KB
20180404 Patiëntenversie Bijnierschorsinsufficiëntie (versie 1).pdf	20-04-18	Clëntenversie	361,04 KB
20180404 Patiëntenversie generieke module arbeidsparticipatie huisstijl (versie 1).pdf	20-04-18	Clëntenversie	240,11 KB
20180404 Patiëntenversie generieke module Diagnostiek huisstijl (versie 1).pdf	20-04-18	Clëntenversie	419,31 KB
20180404 Patiëntenversie generieke module medicatie op maat (versie 1).pdf	20-04-18	Clëntenversie	184,12 KB
20180404 Patiëntenversie_bijnierschorscarcinoom (versie 1).pdf	20-04-18	Clëntenversie	145,2 KB
20180404 Patiëntenversie_feochromocytoom (versie 1).pdf	20-04-18	Clëntenversie	244,7 KB
20180404 Patiëntenversie_primairhyperaldosteronisme (versie 1).pdf	20-04-18	Clëntenversie	310,09 KB
20180404 Patiëntenversie_syndroom van Cushing (versie 1).pdf	20-04-18	Clëntenversie	221,05 KB
20180404 Start Patiëntenversie generieke module zorgagenda (versie 1).pdf	20-04-18	Clëntenversie	267 KB
ABForm_KS_Kwaliteitsstandaard Bijnieraandoeningen (versie 1).pdf		Aanbiedingsformulier	493,84 KB
1 Kwaliteitsstandaard_bijnierziekten.definities in (versie 1).docx	20-04-18	Kwaliteitsstandaard	454 KB

Kwaliteitsstandaarden

Algemene informatie

Status	Gereed
Publicatiedatum	20-04-2018
Wordt er doorontwikkeld	Nee
Contactpersoon	Johan Beun (BijnierNET) info@bijniernet.nl

Omschrijving

In 2016 en 2017 heeft BijnierNET gewerkt aan de ontwikkeling van een kwaliteitsstandaard Bijnieraandoeningen. BijnierNET is een samenwerkingsverband tussen de Bijniervereniging NVACP en de zorgverleners (artsen, verpleegkundigen) van patiënten met bijnieraandoeningen.

BijnierNET is van mening dat iedere patiënt in Nederland met een bijnieraandoening moet kunnen rekenen op zorg van hoge kwaliteit. Hierbij spelen kwaliteitsstandaarden een uiterst belangrijke rol. Derhalve heeft BijnierNET het initiatief genomen om een kwaliteitsstandaard te ontwikkelen voor zorg bij volwassen patiënten met bijnierschorsinsufficiëntie, het syndroom van Cushing, het adrenogenitaal syndroom, primair hyperaldosteronisme en feochromocytoom in samenwerking met de patiëntenorganisaties Bijniervereniging NVACP en de Nederlandse Hypofysestichting, beroepsgroepen van zorgverleners vertegenwoordigd in de NVE, NIV en de koepel VSOP.

In de afgelopen 2 jaar is de kwaliteitsstandaard ontwikkeld met inbreng van velen en onder begeleiding van een klankbordgroep, waarin patiënten en zorgverleners (internist-endocrinologen en verpleegkundigen) uit de UMC's, STZ ziekenhuizen en niet-STZ ziekenhuizen.

Documenten bij kwaliteitsstandaard	Publ. datum	Type	Grootte
Fasen ontwikkeling.docx	17-08-16	Overige	35,16 KB
Samenstelling werkgroep.docx	17-08-16	Overige	19,9 KB
Algemene informatie.docx	20-04-18	Overige	21,39 KB
Criterium 1.docx	20-04-18	Overige	24,77 KB
Criterium 2.docx	20-04-18	Overige	21,32 KB
Criterium 3.docx	20-04-18	Overige	23,88 KB
Criterium 4.docx	20-04-18	Overige	22,44 KB
Criterium 5.docx	20-04-18	Overige	20,59 KB
Overzichts criterium.docx	20-04-18	Overige	20,54 KB

Links bij kwaliteitsstandaard

Links bij kwaliteitsstandaard	Publ. datum	Type
→ Concept KS op website van BijnierNET	17-08-16	Kwaliteitsstandaard

Beoordeling kwaliteitsstandaard op 04 september 2018 door Zorginstituut Nederland

- ✓ Betrokken partijen
- ✓ Beschrijving zorg & organisatie
- ✓ Volledigheid kwaliteitsstandaard

→ [Bekijk uitgebreide beoordeling](#)

Actueel

17 augustus 2016 [Ontwikkeling kwaliteitsstandaard bijnieraandoeningen](#)

Betrokken partijen

Bijniernet
Nederlandse Internisten Vereniging (NIV)
Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP)
Bijniervereniging NVACP
Nederlandse Hypofysestichting
Nederlandse Vereniging voor Endocrinologie (NVE)

Zie ook

Proclaimer

Zorginstituut Nederland is verantwoordelijk voor de inhoud van deze website en doet er alles aan om deze actueel en juist te houden. Zorginstituut Nederland is echter niet verantwoordelijk voor de juistheid van de inhoud die door derden is aangeleverd voor de Kwaliteitsbibliotheek respectievelijk het Register.

→ [Lees meer](#)



Ik wil mijn kwaliteitsproduct(en) publiceren of bewerken
Mijn kwaliteitsstandaarden, meetinstrumenten en informatiestandaarden kunnen bijdragen aan kwaliteitsverbetering van zorg.

Details of this registration can be found at (sorry only in Dutch):

<https://www.zorginzicht.nl/bibliotheek/bijnierziekten/Paginas/Home.aspx>