Implementation and evaluation of personalized care for patients with amyotrophic lateral sclerosis (ALS): ALS Home monitoring & Coaching

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The user experiences of patients and healthcare providers with ‘ALS Home monitoring & Coaching’ are positive.

Ethische beoordeling	Positief advies
Status	Werving gestart
Type aandoening	-
Onderzoekstype	Observationeel onderzoek, zonder invasieve metingen

Samenvatting

ID

NL-OMON25302

Bron
NTR

Verkorte titel
TBA

Aandoening

amyotrophic lateral sclerosis (ALS), progressive muscular atrophy (PMA), primary lateral sclerosis (PLS)

Ondersteuning

Primaire sponsor: University Medical Center Utrecht, Division Neurosciences, Department of Rehabilitation
Overige ondersteuning: ZonMw (number 516006009)

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

The main study parameters will be user experience of both patients and healthcare providers of ‘ALS Home monitoring & Coaching’ in terms of usability, acceptability, appropriateness and feasibility as measured by questionnaires and interviews.

Toelichting onderzoek

Achtergrond van het onderzoek

Background:
The e-health innovation ‘ALS Home monitoring & Coaching’ that has been developed by and implemented in UMC Utrecht in 2016, will now be implemented in 10 multidisciplinary ALS teams that are part of the ALS Care Network in the Netherlands. ‘ALS Home monitoring & Coaching’ is a care innovation for patients with ALS, PMA and PLS based on home monitoring of relevant aspects of functioning (such as walking, dressing, swallowing and breathing), body weight and quality of life. Patients transfer these monitoring data through a (web)app to their care providers. The (web)app also allows the patient to chat with the health care professional. The monitoring data is viewed by a dedicated health care provider (nurse specialist or other member of the multidisciplinary ALS team) who, in consultation with the rehabilitation specialist and the ALS team, takes action if necessary, such as giving advice, providing information, and making an appointment with other healthcare professionals within the ALS care team.

Aim:
The aim of this project is to evaluate the implementation and user experiences of both patients and healthcare providers that have been using ‘ALS Home monitoring & Coaching’.

Methods:
The implementation of ‘ALS Home monitoring & Coaching’ will be done with an Action Research based approach, taking into account local preferences, facilitators and barriers. The implementation in each ALS care team consists of three stages with a total duration of approximately 5-6 months. In the first phase we will explore the starting point and the expected barriers and facilitators. The second phase will be characterized by developing strategies to deal with the expected barriers. In the last phase the ALS care teams will include 10 patients and provide care with ‘ALS Home monitoring & Coaching’. After approximately three months the implementation outcomes and user experiences will be evaluated using both qualitative (e.g. focus groups, interviews) and quantitative methods (e.g. online questionnaires, digital observation with the (web)app, document review).

Doel van het onderzoek

The user experiences of patients and healthcare providers with ‘ALS Home monitoring & Coaching’ are positive.

Onderzoeksopzet

The implementation of ALS Home monitoring & Coaching will take place in three cycles. In each cycle, ALS Home monitoring & Coaching will be simultaneously implemented in 2, 4 and 4 ALS care teams respectively. The duration of each cycle is 5-6 months. The approximate time points for each cycle are described below.

T0 = presentation to provide information to the ALS care team
T1 (at 2 weeks after project start)= focus group to explore expected barriers and facilitators
T2 (at 1.5 months after project start) = group discussion to develop strategies to deal with expected barriers
T3 (at 2 months after project start) = start pilot phase by including 10 patients and provide care with 'ALS Home monitoring & Coaching'
T4 (at 5 months after project start) = to evaluate implementation outcomes and user experiences using both qualitative (e.g. focus groups, interviews) and quantitative methods (e.g. online questionnaires based at the evaluation framework by Proctor, technology acceptance model (TAM) and System Usability Scale (SUS), digital observation with the (web)app, document review)

Onderzoeksproduct en/of interventie

‘ALS Home monitoring & Coaching’ is considered as care innovation not as an intervention.

Contactpersonen

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

- All patients that have been diagnosed with amyotrophic lateral sclerosis (ALS), progressive muscular atrophy (PMA), or primary lateral sclerosis (PLS), that are under the care of one of the ALS care teams can be offered the option to use ‘ALS Home monitoring & Coaching’ for their care. To be eligible for the evaluation of ‘ALS Home monitoring & Coaching’ patients should have consented to use ‘ALS Home monitoring & Coaching’.

- All healthcare providers that have been involved in the care for patients that have been using ‘ALS Home monitoring & Coaching’ are eligible to participate.

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

Patients or healthcare providers who do not speak Dutch cannot participate, because the (web)app is only available in Dutch (at this moment).

Onderzoeksopzet

Opzet

Type:	Observationeel onderzoek, zonder invasieve metingen
Onderzoeksmodel:	Anders
Toewijzing:	N.v.t. / één studie arm
Blindering:	Open / niet geblindeerd
Controle:	N.v.t. / onbekend

Deelname

Nederland

Status:	Werving gestart
(Verwachte) startdatum:	01-02-2020
Aantal proefpersonen:	100
Type:	Verwachte startdatum

Voornemen beschikbaar stellen Individuele Patiënten Data (IPD)

Wordt de data na het onderzoek gedeeld: Nee

Toelichting
N/A

Ethische beoordeling

Positief advies

Datum:	15-04-2020
Soort:	Eerste indiening

Registraties

Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

In overige registers

Register	ID
NTR-new	NL8542
Ander register	METC UMC Utrecht : METC 20-204/C

Resultaten

Samenvatting resultaten
N/A