

# ARIA Project

## Author/reference person

Giorgio Vezzani - Arcispedale Santa Maria Nuova Reggio Emilia - [Giorgio.Vezzani@asmn.re.it](mailto:Giorgio.Vezzani@asmn.re.it)

## BACKGROUND AND AIMS / TYPE OF INNOVATION

Pulmonary complications are the main cause of morbidity and mortality in neuromuscular and in severe rib cage diseases patients.

Patients with neurological, neuromuscular and severe chest wall diseases with chronic respiratory failure treated with mechanical ventilation with or without tracheostomy and with or without supplemental oxygen have a very poor prognosis and a limited life time free from respiratory complications. They generally do have significant limitations on their social life because of frequent hospital admissions for acute respiratory complications which worsen further, sometimes to the death, their respiratory and global health condition.

The ARIA Project is the development of an idea born within the Italian Association of muscular dystrophy patients (UILDM) by some medical specialists in pulmonology, belonging to the Arcispedale Santa Maria Nuova (Santa Maria Nuova General Hospital) in Reggio Emilia and to the San Sebastiano Hospital-Local Health Authority of Reggio Emilia, who have long dedicated themselves to the care and follow up of acute and chronic respiratory failure in neuromuscular, neurological and rib cage diseases patients.

In particular the project, started in 2008 and still ongoing, aims to evaluate the feasibility of an innovative home follow up program combining tele-monitoring and chest physiotherapy in preventing and early treating acute respiratory episodes, in order to avoid/to reduce hospitalization and to maintain good clinical condition as long as possible in such fragile patients. Tele-medicine is an important innovative and powerful tool that can contribute to deliver benefits to patients, caregivers and health workers to improve collaboration among them, earlier clinical decisions, fragile patients' quality of life, patients' independent daily life, patients' life length, healthcare costs cutting.

The ARIA Project demonstrates that a continuous remote clinical conditions monitoring in really fragile outpatients allow to obtain: a physiological tranquillity for patients and their families, a useful clinical decision support to the patients' GP, a significant reduction in hospital admissions for acute respiratory diseases, a cutting of healthcare costs.

In fact neurological, neuromuscular, and rib cage diseases affected patients that often suffer from acute respiratory failure usually causing hospitalization in high care settings for a long time. Early home tele-monitoring detection of worsening of the clinical conditions in such fragile patients may allow an earlier medical and chest physiotherapy treatment at their home setting, avoiding to reach critical clinical conditions. This can reach two very important goals: to allow patients to remain at their home during acute respiratory exacerbations therapy and to cut healthcare costs, avoiding high care hospitalization.

With reference to the different Project's steps, patients and their caregivers were initially submitted to an educational meeting in hospital; at home they had to daily register respiratory signs and symptoms. Each patient was equipped with a clinical respiratory 10-item questionnaire and with a pulse oximeter with a modem for transmitting data to a remote control center in charge of alerting the pulmonologist in case of early sign and symptom deterioration. Patients' GP and chest physiotherapy interventions at home were planned after pulmonologist indication. So, as a consequence of these actions, patients were allowed to earn up to now four years of life in good health and independence from the hospital and were able to have a social life unimaginable with the previous model of care.

Integration of early detection of pathological symptoms and respiratory parameters by mean of tele-monitoring, early medical and chest physiotherapy treatments in a home based setting may allow a greater independent living to particularly vulnerable patients than the traditional hospital care and cure model. Moreover, the reduction of the number of acute respiratory complications may allow to maintain good health conditions as long as possible, with very favourable impact on social and occupational daily life and on life length.

## SCALABILITY-REPLICABILITY, TRASFERIBILITY

Given the excellent results achieved so far by the ARIA Project, there is the intention to propose its spread to all Pneumologic and Neurologic Wards in the Emilia-Romagna Region and also enter patients with amyotrophic lateral sclerosis, quadriplegia and Gold stage IV COPD. To this end, meetings with the heads of Pneumologic Wards sited in the hospitals of Emilia-Romagna as well as Local Health Trusts have been scheduled and then, with the aim to scale-up the ARIA Project in the provinces of the Region, the home-based service providers will be contacted to standardize assistance and home monitoring procedures.

The ARIA Project currently involves many actors: hospital specialist pulmonologists, patient's general practitioners, chest physiotherapist, patients, their families/caregivers, home service providers, hospital management and the leadership of Local Health Trust. In the next project development phase, specialist neurologists and specialists in neuro rehabilitation will be involved.

It can be assumed that after spreading and testing the ARIA Project in other provinces of the Region, this care model should be proposed to other Italian or EU Local Health Trusts or Regions to join the Project.

## OUTCOMES

The long term traditional care of patients enrolled by the ARIA Project is very expensive for Health Public Service, as these patients frequently need hospitalization in intensive care settings for long periods.

Hospitalization costs in Santa Maria Nuova General Hospital at Reggio Emilia due to acute respiratory failure are: € 300 per day in a Pneumologic Ward, and € 2,000 per day in a high Intensive Care Unit.

The average annual cost per patient involved in the ARIA Project (including telemedicine service and to house visits of the respiratory physiotherapist) is around € 1,200.

The ARIA Project continues to demonstrate, since 2008, that more human, much less expensive and more preferably treatment of patients with different kinds of highly disabling diseases, is possible compared to the classical scheme of hospital care. So it is possible to assume a substantial savings for the regional health expenditures, especially for larger numbers of highly fragile patients cared for in their own homes.

The spread of home care settings forces the industry to propose new telecommunication and remote monitoring devices, to gain physiological parameters with as user friendly as possible biometric sensors. The ARIA Project contributes to the dissemination and using of these new sophisticated technologies, potentially contributing to their improvement through field trials.

Currently the number of patients cared for by ARIA Project is small,\* but there is the aim to extend both the range of diseases serviceable remotely at home and the number of patients.

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\* Fourteen patients are currently enrolled in the ARIA Project (age: mean 38,7 ± 15,8, min 17 max 68; mechanical ventilated (MV) patients: 11 (78,5%), patients in oxygen therapy plus MV: 3 (21,5%), patients with tracheostomy: 6 (42,8%).

The diseases included are: Becker muscular dystrophy (MD) 1, Duchenne MD 4, other congenital MD 2, scapular-humeral girdle MD 2, Welander distal MD 1, pompe's disease 1, other myopathy 1, Type 2 spinal cord amyotrophy 1, severe Kyphoscoliosis 1.

Admission criteria are: Reduced cough power (PCEF < 270 l/min), MEP < 40 cm H<sub>2</sub>O, CV < 1500 ml, Adequate home caregiver support, Hospital access difficulty (excessive distance, greatly reduced or entirely absence of personal physical mobility capacity), Mechanical Home Ventilation. Exclusion criteria are: bulbar muscular impairment, no pt's cooperation, poor pt's and relatives motivation.