

CONFERENCE ABSTRACT

Making a business case of the NeMO (Neuromuscular Ominicentre) experience to understand when and how sustainability can rely on the patient-centricity and service co-production

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The paper presents an in-depth business case study of the NEMO Centre in Italy, a healthcare no-profit organisation that provides highly specialised services for neuromuscular diseases, for adults and children. NEMO started in 2008 as the first centre targeted to these complex patients who could not find any integrated care answer in the public or private sector nor services concentrating the multi-disciplinary competences and expertise required. The NEMO Centre rose from the collaboration of patients' associations, which established a No-profit Foundation, that sought for managing and contracting partnership with public hospitals wherein the NEMO Centre and the new service delivery model have been set up. In seven years, the Centre has constantly grown, yet enlarging the volumes and services provided, yet opening three new centres in other Regions to cover broader geographical areas. The NEMO growth indeed proved the successful results achieved by its service delivery model. It succeeded in covering previous unmet needs with high efficacy and with great efficiency and sustainability based on the institutional public-no profit partnership design. The paper thus provides the methodological approach adopted for building a business case study, focusing on two NEMO Centres and gathering quantitative and qualitative data from two Integrated Care Pathways (ICPs) – one on the Amyotrophic Lateral Sclerosis (adults) and one on the Duchenne Muscular Dystrophy (children). The business case framework indeed applied the model of the People Powered Health to value yet the results of efficacious care yet the implications for improving the services' delivery through the co-production and co-design.

Results provides interesting lesson learnt over the NEMO experience as well generalizable implications for the scaling up and spread-out of similar experiences. Whereas there are robust proves of efficacious care provided, indeed able to strengthen personalization and integration of services to meet individual and family's needs (patient centricity), the future sustainability of the service model requires the development yet of the public-sector culture yet of the managerial maturity and positioning of the patients' associations' board (the foundation). The new enlargements, propelled by the associations, clash with the need of structuring and formalizing an inter-organisational network of expert Centres. The new Centres in fact

Morando; Making a business case of the NeMO (Neuromuscular Ominicentre) experience to understand when and how sustainability can rely on the patient-centricity and service co-production

exploited heterogeneous institutional designs drawn by the emergency and due to different contextual factors, political and regulatory ones. As a result, today this variety is challenging the efficiency and effectiveness of the original model.

The successful attainments of partnerships between private no-profit and the public need to be fueled over time and get to establishing formalised models, beyond the nature of piloting projects. These lessons learnt and detailed recommendations are discussed in the paper moving from the data gathered and the interviews run with key stakeholders and policy makers involved in the NEMO experience.

Keywords: neuromuscular conditions; omniservice model; patient centricity; co-design; co-production; public-private partnership; people powered health (pph)
