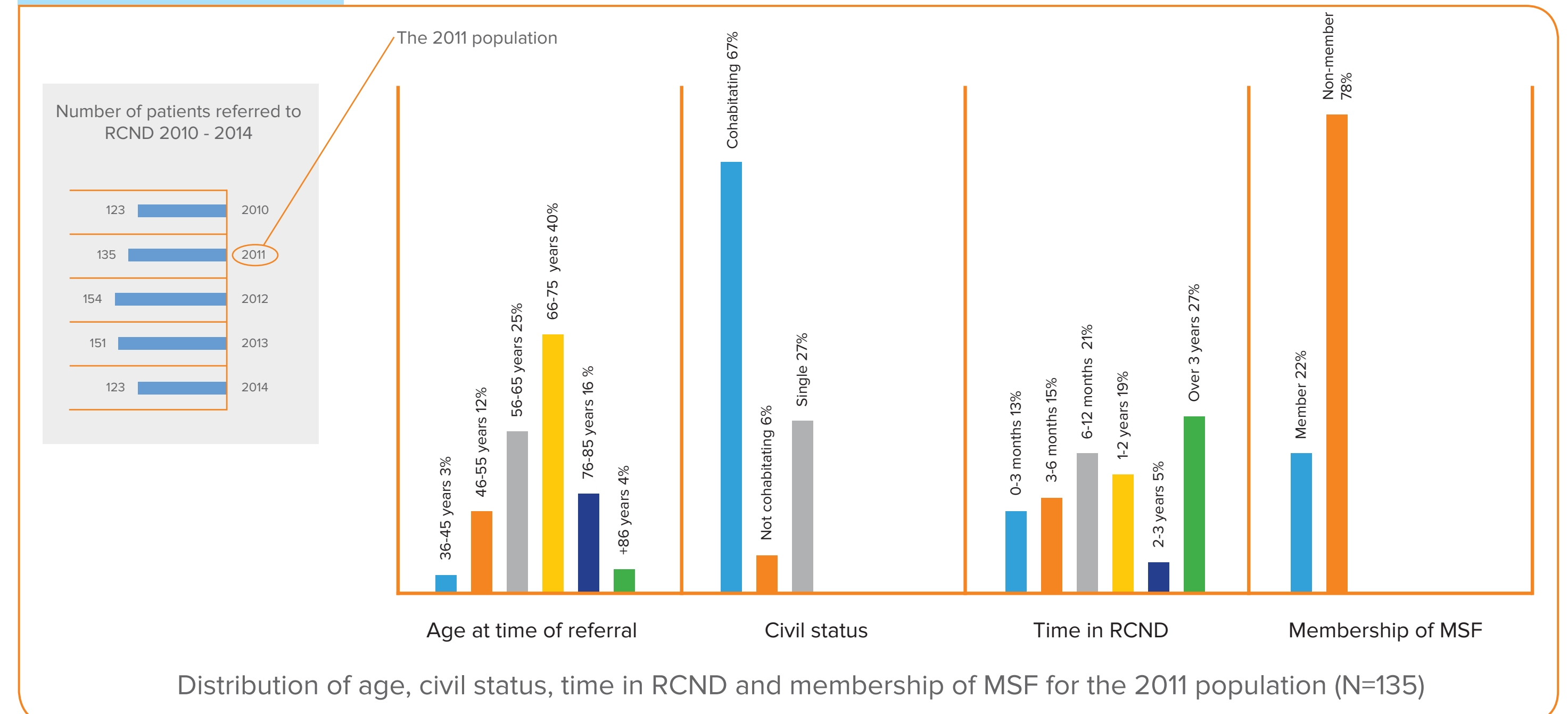


BACKGROUND

Ninety-five percent of all people diagnosed with ALS in Denmark accept referral from the hospital to the national Rehabilitation Centre for Neuro-muscular Diseases (RCND). In line with recommendations¹⁾ to establish a co-ordinating interface between neurology, rehabilitation and palliative care, this centre develops and supports multidisciplinary approaches in rehabilitation and palliation, both at a personal, family and community level. The individual use of specific RCND services in relation to disease progression and other key variables has not been studied systematically.

¹⁾ Ng L, Khan F. Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease. Cochrane Database of Systematic Reviews 2009, Issue 4. Art. No.: CD007425. DOI: 0.1002/14651858.CD007425.pub2

FIGURE 1



OBJECTIVES

To describe, quantify, and assess the use of 11 key RCND services in relation to age, civil status, time in RCND, and membership of the disability organisation Muskelsvindfonden (MSF).

METHODS

A descriptive statistical 4-years (2011-2014) follow-up profile of the individual use of RCND services in a total one calendar year cohort of patients with ALS referred to RCND.

FIGURE 2



FIGURE 3

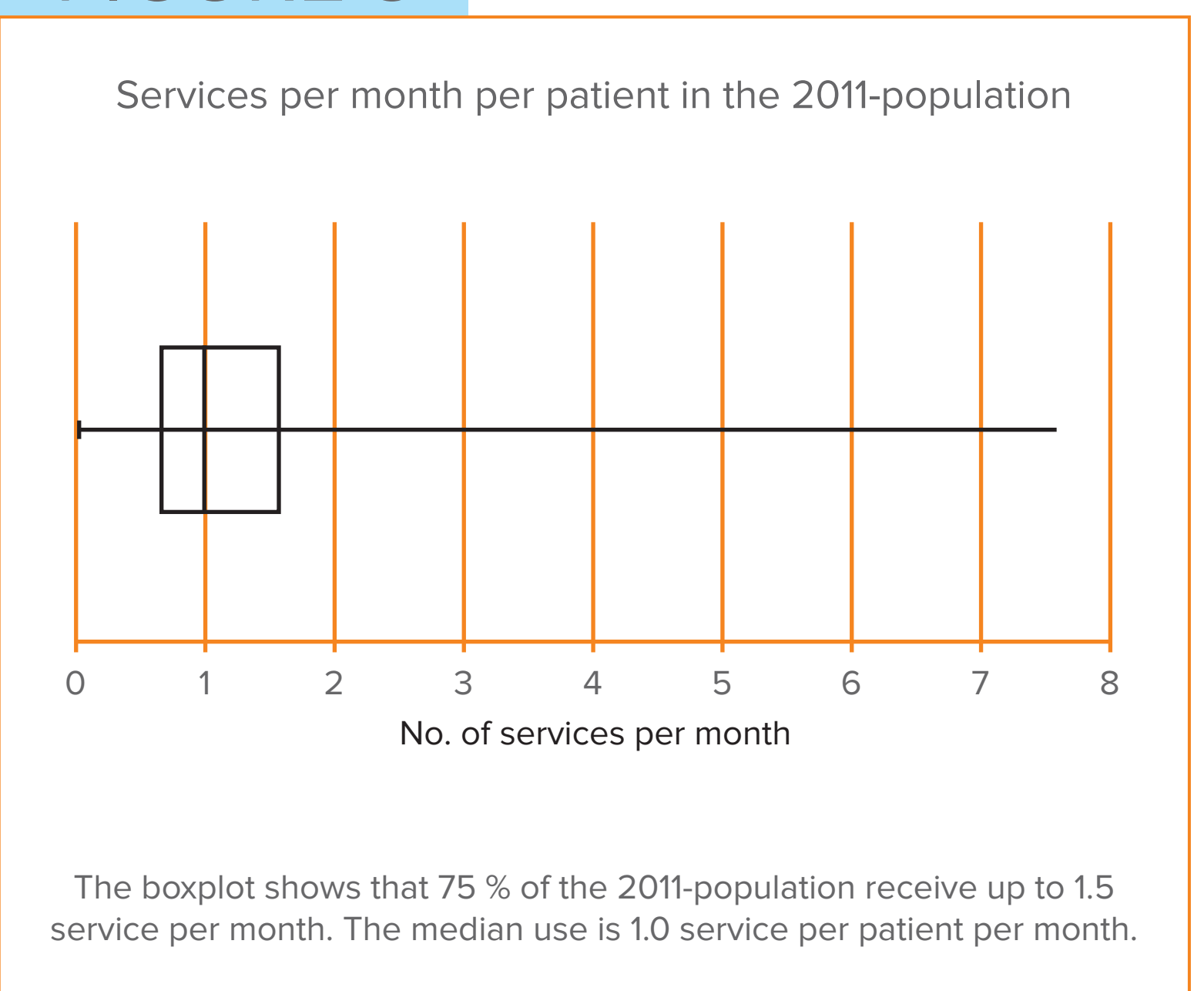
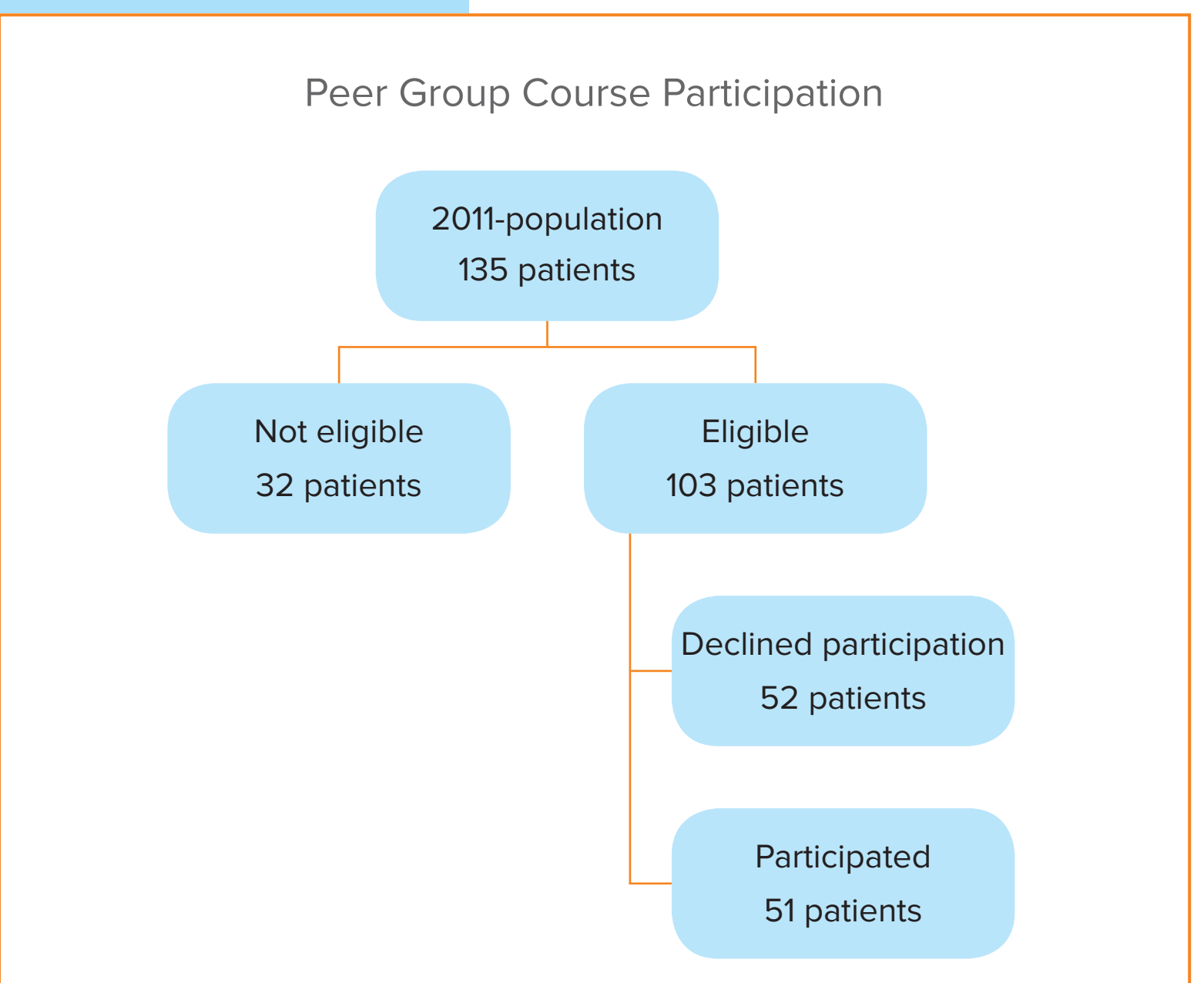


FIGURE 4



RESULTS

All patients with ALS (N=135) referred to RCND in 2011 was identified (Figure 1). The total and individual use of 11 key services in the period 1 January 2011 to 31 December 2014 was retrieved from RCND records (Figure 2, Figure 3).

The individual use was calculated in relation to age, civil status, time in RCND, and membership of MSF.

Patterns of individual use mirrored variability in relation to age and disease progression, but also proved earlier assumptions to be wrong, for example regarding the actual proportion of patients participating in peer group courses which turned out to be about 50 percent of eligible patients (Figure 4).

DISCUSSION

The proportion (50%) of eligible patients participating in peer group courses shows the importance of identification of relevant target groups, focus on sign up procedures, and carefully tailored content and configuration of courses.

CONCLUSIONS

The high referral percentage indicates a need for the RCND as a specialised interface between rehabilitation, palliative care, and ALS hospital-teams.

The 4-years follow-up profiles of the use of services confirmed the existence of subgroups with well-known needs for support and rehabilitation. The study underlined that complexity in each case is a standard challenge in ALS rehabilitation. It means that standardization of procedures, interventions, and programmes is limited. Preadmission assessment to services must carefully take into account the individual complexity.

