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quantification of the burden of care.

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- ¹ See Appendix A.

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28 1. Introduction

29 The dependency of a person is defined as their total or partial 30 inability to perform activities required for daily living without help due to activity limitations in the normal environment. The 32 consequence is a restriction in participation, in terms of the 33 International Classification of Functioning, Disability and Health 34 (ICF) [1].

35 For hospitalizations in rehabilitation centers (RCs), given the 36 pathologies of patients and lengths of hospitalization, the 37 dependence of the patient must take into account both motor 38 and cognitive aspects when quantifying the activity of the 39 healthcare staff. The limitations of the patient's activity affect 40 the provision of care (basic or relational) by nursing staff and the 41 performance of reeducation and rehabilitation activities by 42 therapists (modification of the installation time in the reeducation 43 room, fatigability, behavioral disorders, etc.). Cognitive depen-44 dence should not be disregarded because it can be a care burden for 45 healthcare professionals, at least as important as physical 46 dependence. Therefore, dependence in all its aspects should be 47 accounted for when quantifying the medical and paramedical 48 activity of a department. The relation between dependence and 49 burden of care must be explored because although they are 50 obviously linked, they are not equivalent. For example, the burden 51 of care could be lighter if a patient has to be totally washed as 52 compared with a patient who has to be stimulated during the washing

53 54 In physical and rehabilitation medicine (PRM), in which the 55 evaluation is central and dependence a priority for action for 56 therapeutic interventions, many validated scales are used to assess 57 the dependence of patients. Some of these, such as the Barthel 58 Index [2], validated for patients with neurological post-stroke, or 59 the Instrumental Activities of Daily Living [3] mainly used in 60 geriatric RCs, are more specific to a particular population. The 61 Functional Independence Measure (FIM) [4], with its pediatric 62 version, the WeeFIM [5], is more often used in RCs. It has good 63 metrological qualities and allows for measuring both the level of 64 physical and cognitive activity. It consists of a rater-administered 65 assessment of performance (measurement of what the patient 66 actually does, as opposed to measurement of abilities exploring the 67 maximum that the patient can do) investigating 6 domains divided 68 into 13 items for motricity and 5 items for cognition. Each item is 69 rated on 7 levels, based on the need for technical help, monitoring 70 or required help [4,6–9]. Although the FIM is adapted for several 71 diseases [5,6,8,10], it has limitations for low back pain, shoulder 72 disorders [4], as well as vascular and respiratory diseases 73 [11]. Because of the length of time required to administer the 74 scale in French (from 30 to 45 min) [12], its routine use is difficult 75 for quantifying the dependency of each hospitalized patient.

76 In France, as part of the collection of medical and administrative 77 data for patients (Programme de médicalisation des systèmes 78 d'information [PMSI]) [13], dependence has been assessed in RCs 79 since 1997 by use of a French scale, the Activité de la Vie Quotidienne 80 (AVQ), composed of 6 items (4 physical items and 2 cognitive 81 items). However, this scale has never been validated [14] and many 82 practitioners criticize particularly the lack of standardized 83 guidance, a suspected large floor effect, the under-evaluation of 84 the cognitive dependence, and the unsuitability or even un-85 usability in some populations, especially pediatrics.

86 Given the limitations of existing scales, in 2015, the French 87 society for PRM (SOFMER) proposed to create and validate a new 88 classification of activity measurement based on the ICF model, the 89 SOFMER Activity Score (SAS). The SAS was to be easy to use, allow 90 for rapid generation of a score and be adapted for use during a 91 multidisciplinary review meeting, while avoiding a floor effect and 92 providing a good and reproducible description of the physical and

93 cognitive dependence of pediatric and adult patients hospitalized in RCs. If the SAS showed good metrological properties and was 94 able to quantify the burden of care well, it could be used for clinical 95 practice and could better identify the resources required for 96 hospital care in a medical or economic approach. 97

Here, we present the construction of the SAS, an analysis of the validity of the content, and the results of a feasibility study, which is a preliminary step before validation studies.

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2. Materials and methods

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The different development stages of the SAS are described in 102 103 Fig. 1.

2.1. Construction of the first version of the SAS

105 An exhaustive review of the literature related to the different tools used for evaluating the dependence of hospitalized patients 106 was performed. A working group consisting of 4 PMR physicians, 107 2 healthcare managers, 1 childcare assistant, 1 physiotherapist, 108 1 senior hospital technician and 1 clinical research associate was 109 involved in developing the first version of the SAS (called SAS_V1) 110 during 2 meetings between May and June 2015. Two members of 111 the group had purely pediatric experience and 6 had experience 112 with adults and/or geriatrics. The years of experience ranged from 113 6 to 25 (mean 13.7). 114 115

The different scoring fields (headings and descriptions of the activity fields) were adapted from the ICF activity fields, with a proposition of 4 fields for physical activities ("Hygiene, dressing", "Mobility", "Feeding", "Elimination") and 4 fields for cognitive activities ("Communication", "Memory, learning", "Relationships with others", "Judgment, initiative and control of activity").

For each of the activity fields, the working group proposed a 5level classification system for the activities (Level 1: "Activity possible without help", Level 2: "Activity possible with technical help and/or adjustment but without human help", Level 3: "Activity possible with human help", Level 4: "Activity possible with continuous human help", Level 5: "Activity impossible regardless of help").

To help with the scoring, a section "Introduction and instructions for the user" specifies the scoring methods, and clinical thumbnail images were proposed to illustrate the practical use of the scoring.

The scoring was tested by members of the working group on 132 33 patients hospitalized in RCs to perform an experimental study. 133

2.2. Analysis of the validity of the content: Delphi method

To analyze the validity of the content of the proposed SAS_V1, 135 the Delphi method [15–17] was used via email. This stage allowed 136 for collecting the opinion and comments of several French PMR 137 experts concerning the relevance of the scoring's content, 138 particularly the relevance of the fields selected and their scoring 139 procedure.

Overall, 32 physicians or healthcare professionals known for 141 their expertise in PMR and not having participated in the first 142 phase of the study, were invited to participate; 26 responded to the 143 first round of Delphi (10 PRM physicians, 3 geriatricians, 3 pedia-144 tricians, 2 Department of Medical Information doctors, 2 hospital 145 directors, 1 general practitioner, 2 heads of physiotherapy, 146 2 occupational therapists and 1 director of the department of 147 nursing). Eight participants had expertise in pediatrics, 20 in adult 148 patients and 8 in geriatrics; 10 experts practiced in a public 149 establishment and 16 in a private establishment. Their experience 150 in the field of PMR ranged from 2 to 35 years (mean [SD] 19.9 [10.3] 151 152 years).

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