



Provision and financing of assistive technology devices in Germany: A bureaucratic odyssey?

The case of Amyotrophic Lateral Sclerosis and Duchenne Muscular Dystrophy

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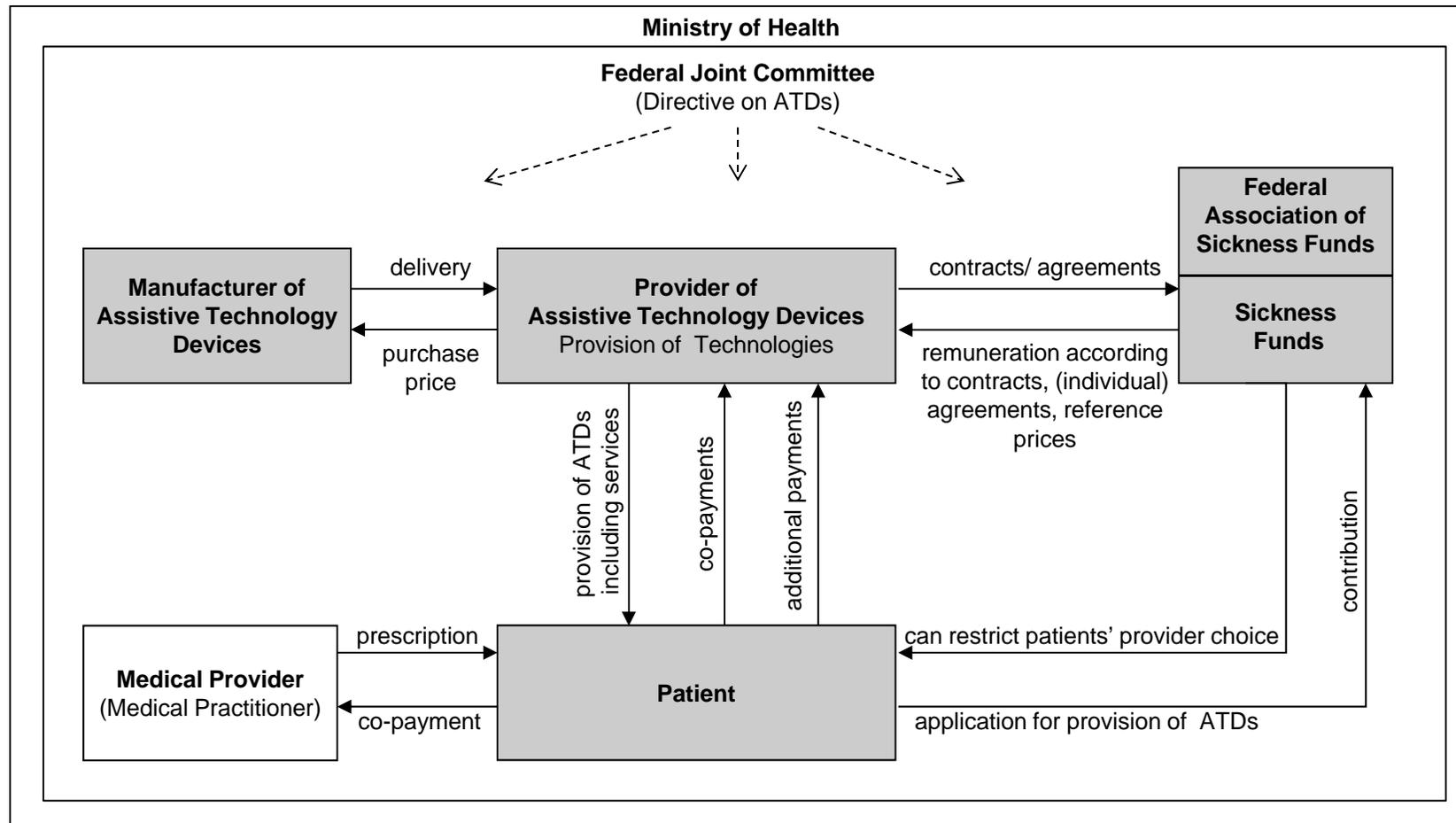
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- assistive technology devices (ATDs):
 - to mitigate/ eliminate barriers to independence in individuals with disabilities
 - to ameliorate mobility, communication and house-environment management
- crucial for functional independence, maintenance of physical and mental health, and selfcare
- adequate provision and financing of ATDs:
particularly important for people suffering from diseases with a high and ongoing need for these technologies
 - Amyotrophic lateral sclerosis (ALS)
 - Duchenne muscular dystrophy (DMD)

The provision of assistive technology devices

Payment flows and supply chain activities



- affecting less than 5 out of 10000 people
 - limited availability of special care providers with expert knowledge
- ALS** - a neurodegenerative disorder of unknown etiology
- characterized by rapidly progressive muscular paralysis, which leads to death within 3 to 5 years of symptom onset
- DMD** - a chromosome-linked recessive disorder
- defect of dystrophin: loss of independent ambulation in the early teenage years and subsequent respiratory insufficiency and dilatative cardiomyopathy in the second decade of life
- neither of these rare diseases can be cured nor can their progression be reversed or stopped

- Literature concerning the management of ALS and DMD mentions the importance of ATDs for patients with ALS and DMD
 - However, nothing is known about problems in providing and financing ATDs for people with these diseases
- Aim: exploring and analyzing patients' problems with the provision and financing of ATDs for these two rare diseases

Design and participants

- qualitative content analyses to investigate patients' experiences with the provision and financing of their ATDs
- 19 ALS and 14 DMD patients were interviewed

Data collection

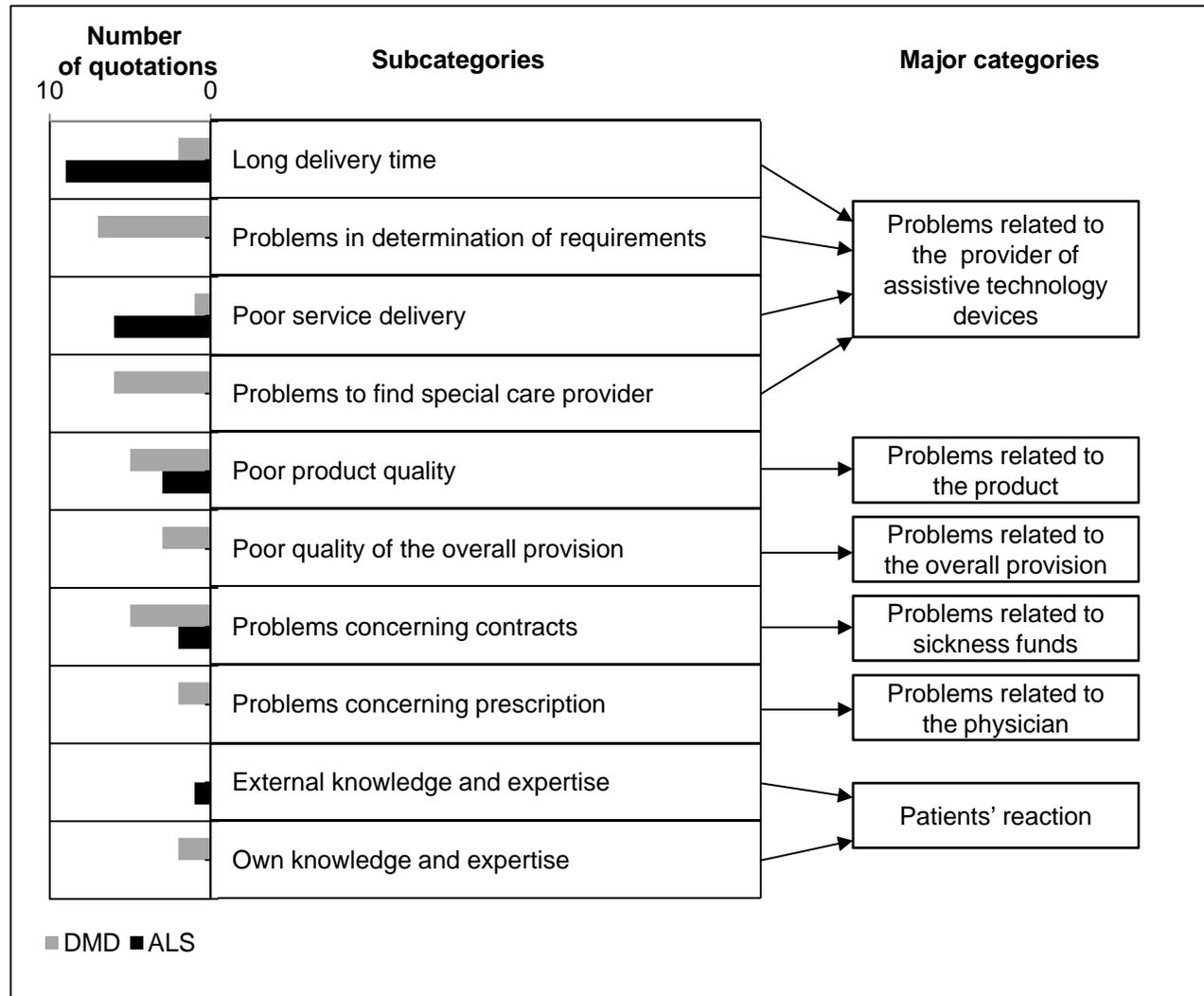
- semi-structured one-to-one phone interviews
- questions concerning patients' satisfaction with the provision of assistive technologies (special regard to the availability and quality of products and services)
- barriers in the context of the sickness fund's decision to pay for ATDs

Data analysis

- transcripts: coded and analyzed using Atlas.ti version 6.2
- development of a coding scheme: qualitative content analysis
- inductive category development: categories derived inductively from the text that is analyzed
- categories are based on study questions that were determined a priori:
 - (1) problems regarding provision of ATDs and
 - (2) problems concerning the financing of ATDs from patients' viewpoints
- subcategories were further reduced to main categories
- extra codes for new themes that arose: patients' reactions to problems with provision and financing of ATDs

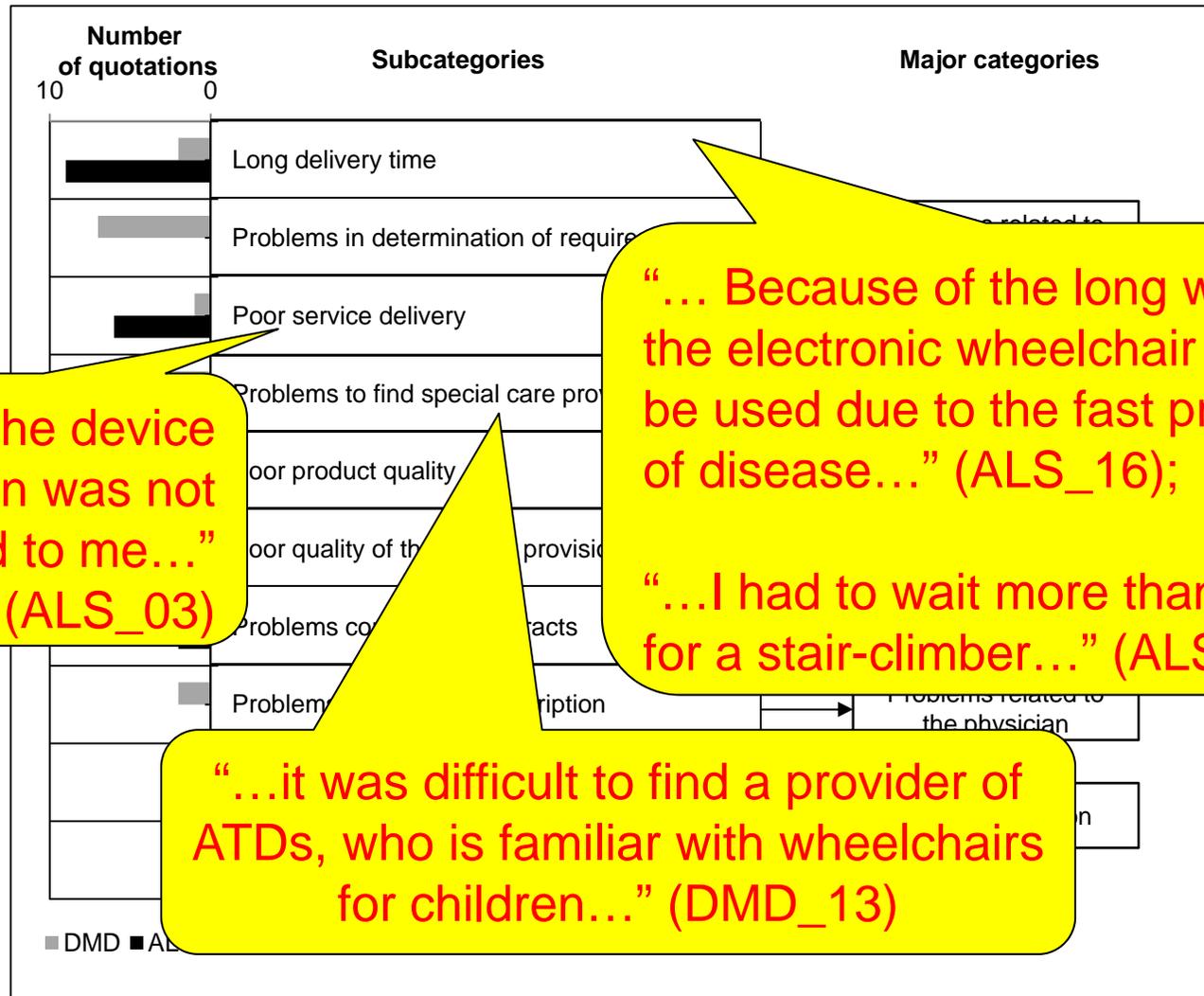
Results I

Problems regarding the provision of ATDs from patients' view



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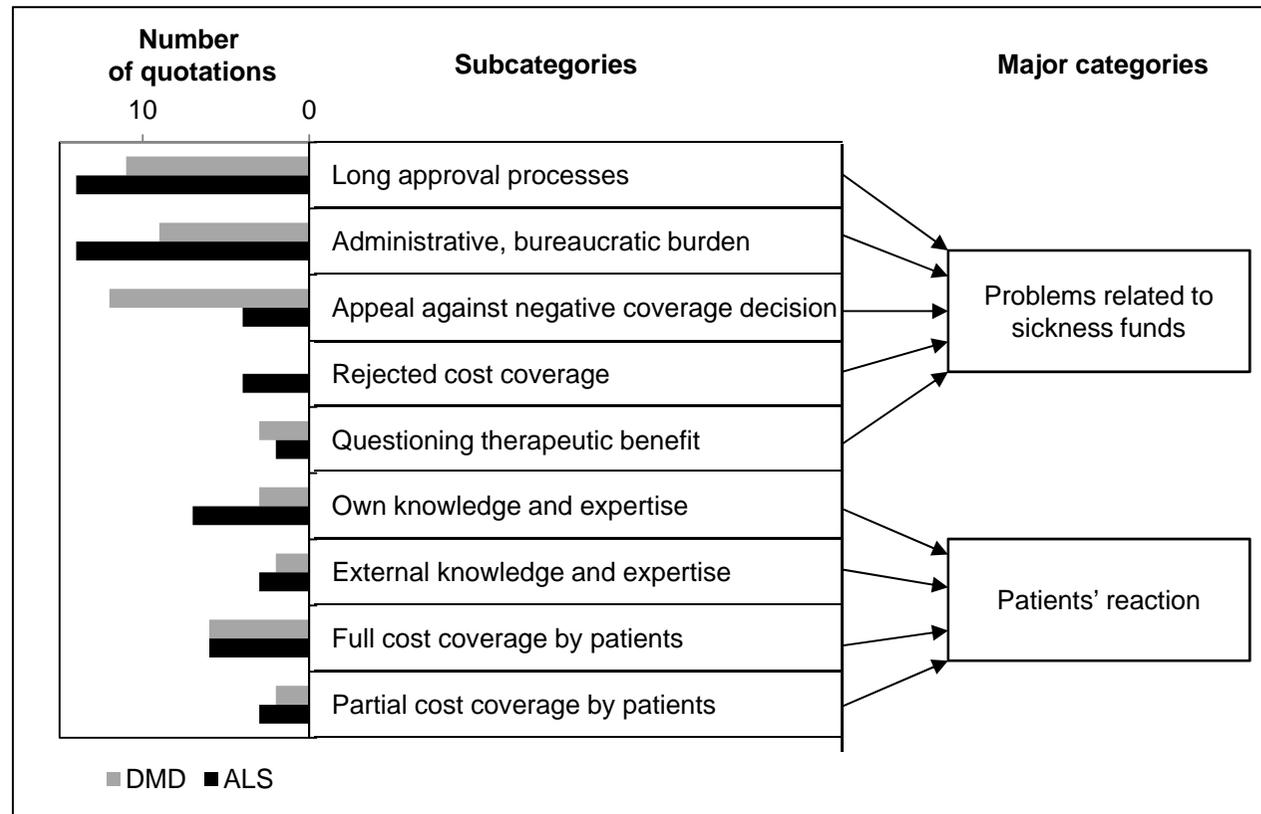
“...The device operation was not explained to me...” (ALS_03)

“... Because of the long waiting time, the electronic wheelchair could not be used due to the fast progression of disease...” (ALS_16);
 “...I had to wait more than 3 months for a stair-climber...” (ALS_01)

“...it was difficult to find a provider of ATDs, who is familiar with wheelchairs for children...” (DMD_13)

Results II

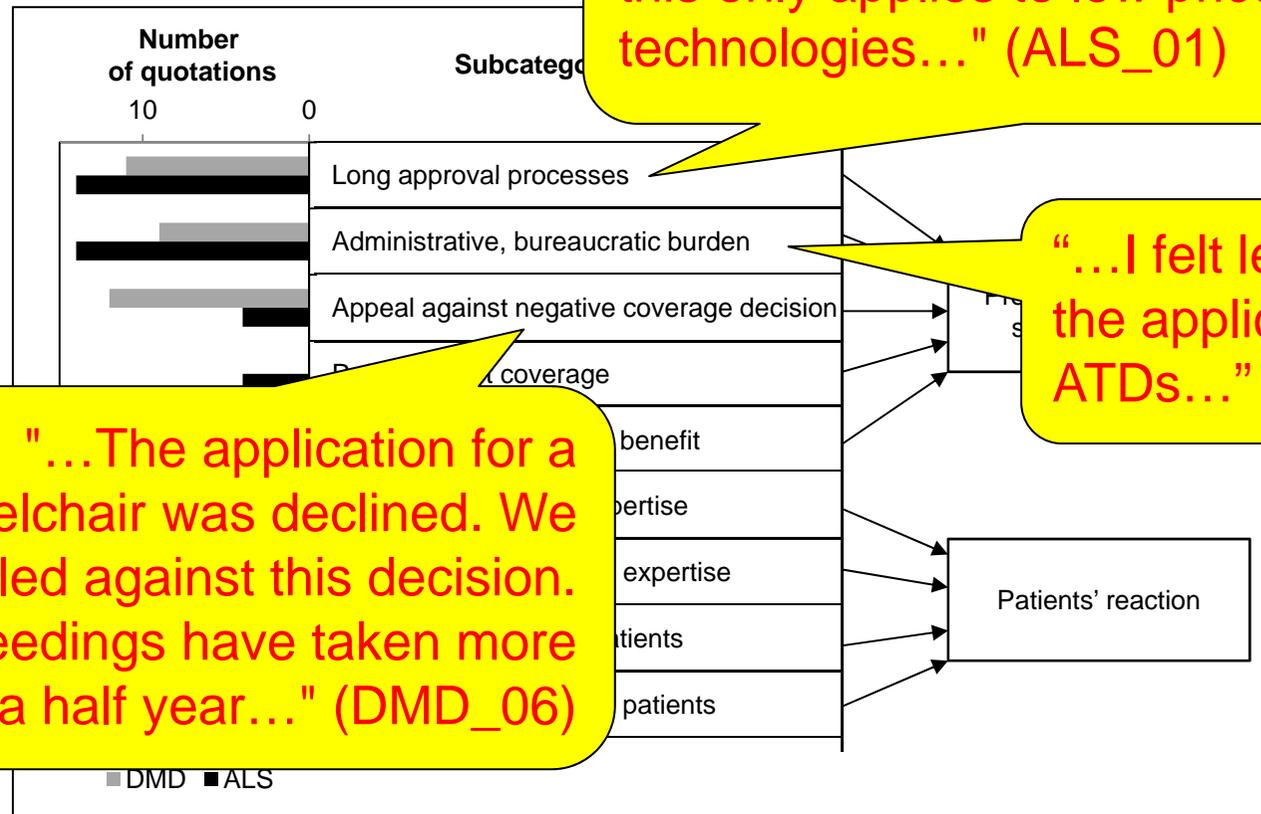
Problems regarding the financing of ATDs from patients' view



Results II

Problems regarding the financing

"...For the first time financing of assistive technologies was no problem. However, this only applies to low priced assistive technologies..." (ALS_01)



"...The application for a wheelchair was declined. We appealed against this decision. Proceedings have taken more than a half year..." (DMD_06)

"...I felt left alone with the application for ATDs..." (ALS_02)

Patients' reaction

- problems with patients' provision of assistive technologies concern almost all stakeholders involved in the provision process
- main difficulties: long delivery times and problems in the determination of requirements
- because of the fast progression of ALS and DMD, it is highly important for patients to be provided with adequate assistive technologies immediately
- long approval processes of sickness funds and patients' administrative bureaucratic burden are the hurdles most often experienced by patients

- precise guidelines for patients, prescribing physicians, providers of ATDs, and sickness funds should be introduced
- case managers acting as "system agents" might coordinate system resources for patients and are accountable for successful patient movement through the system
- due to the low incidence of ALS and DMD, case management should be adopted for patient groups taking into account a range of diseases that have a high need for ATDs
- "brokerage model": case managers primarily act as enablers, system coordinators and brokers of services
- those case managers typically have large case loads, with a volume of 50, and are office based

- the study relied on the reported experiences of patients
- perceptions of sickness funds might differ, especially in the context of therapeutic benefits for patients
- the number of quotations gives only a global indication of the relative importance that respondents attached to different concepts
- quantitative interpretations (e.g. in terms of percentages) should not be derived from these quotations
- the intensity of the use of ATDs differs according to the severity within both diseases

- an in-depth understanding of patients' experiences with the provisioning and financing of ATDs
- sickness funds and ATD providers should keep in mind that the need for ATDs is highly complex in people suffering from ALS and DMD
- due to the fast progression of ALS and DMD, patients must be provided with ATDs immediately
- the study provides first findings of problems in providing and financing ATDs for people diagnosed with ALS and DMD in Germany
- especially in the case of rare diseases, EU member states should consider reference networks as focal points for medical training and research, information dissemination and evaluation

Thanks to the audience!

Presentation and further information available at:

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