

Information on the NMD Care Management Concept and the Implementation Phase (project Care-NMD-CH)



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Online Meeting, 06.04.22

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A warm welcome to this presentation

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General Information

- Recording of the presentation via Zoom
- Video will be sent to you afterwards
- Participants from different language regions:
 - Presentation (slides and oral presentation) in English
 - Please ask for translation

Thank you for your collaboration!



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Thank you to the project team

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Thank you to the members of the Sounding Board and Project Partners



[Schweizer Register für neuromuskuläre Erkrankungen](#)

Content

- Project Information
- NMD Care Management Concept (NMD CM)
- Implementation and Evaluation
- Application for participation
- Questions

Background

- Neuromuscular diseases (NMDs) are rare genetic disorders
- Progressive muscle weakness and death at a young age due to loss of function of major organs such as the heart and lungs
- No causal treatments for most NMDs, affected persons and their families experience serious health and psychosocial consequences
- The management of NMD is complex and requires a coordinated, interprofessional care approach

(Amato & Russell, 2008, Birnkrant, Bushby, Bann, Alman, et al., 2018; Birnkrant, Bushby, Bann, Apkon, Blackwell, Brumbaugh, et al., 2018; Birnkrant, Bushby, Bann, Apkon, Blackwell, Colvin, et al., 2018, Wang et al., 2007)

- Uneven resources, lack of expertise in treating rare diseases and inconsistent distribution of specialized services lead to disparities in clinical outcomes
- Care Management (CM) has the potential to optimize care and to reduce costs
- Care Manager can support patients and families and foster interprofessional collaboration through a coordinated, evidence-based, and family-centred approach
- To be effective and sustainable, it is important to implement CM services for NMD patients strategically and sustainably and to highlight its values

(Elliott & Zurynski, 2015; Schieppati et al., 2008; Waldboth et al., 2021; Waldboth et al., 2022)

Purpose and Aims

Phase A

- to investigate the current NMD care situation; to describe the status quo of the practice of care; to identify areas that work well and areas that need attention

Phase B

- to develop an evidence-based and family-centred concept for NMD-Care Management (NMD CM)

Phase C

- to develop a concept for implementing the NMD CM services in selected NMCs
- to implement and evaluate benefit for patients / families, for the interprofessional care team, and at a systems level

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Methods - Phase B

- Literature search and development of a roadmap using a logic model
 - Discussions and feedback from expert group (Sounding Board, workshops, project team)
 - Participatory action research methodology: reflection, planning, action, observation, reflection, planning
- **description of the scope of practice of NMD Care Managers, best practice interventions, collaboration with the interprofessional care team and within the expert networks**

(Silverman et al., 2007; Glasson et al., 2008)



Results – NMD CM Concept

- Introduction
- Clarification of terms
- Aims
- Methods
- Requirements
- Competencies
- Overall Tasks: Coordination and Navigation

Inhaltsverzeichnis

1	Einleitung
1.1	Ausgangslage Projekt Care-NMD-CH
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1.3	Ziele und Forschungsfragen
2	Methode
3	Die komplexe Versorgung von Menschen mit NMD
4	Die Kompetenzen von NMD Care Manager_innen
4.1	Anforderungen an das NMD Care Management
4.2	Kompetenzerwerb
5	Tätigkeitsbereich und Leistungen der NMD Care Manager_innen
5.1	Koordination und Navigation

Direct Clinical Practice

- Collecting information / history
- Symptom Management
- Advanced care planning
- Clarify and inform
- Guide and instruct
- Counsel and consult
- Organise and connect
- Home visits
- Caregiver support
- Psychosocial support

5.2 Bereich A: Direkte klinische Praxis - Leistungen für Betroffene und Familien

- 5.2.1 Care Management Anamnese
- 5.2.2 Symptom- und Selbstmanagement fördern
- 5.2.3 Vorausschauende Planung
- 5.2.4 Aufklärung und Informationen abgeben
- 5.2.5 Anleiten und Instruieren
- 5.2.6 Beratung und Sprechstunde
- 5.2.7 Aufsuchende Dienste und Hausbesuche
- 5.2.8 Organisation und Vernetzung
- 5.2.9 Angehörigensupport
- 5.2.10 Psychosoziale Begleitung und Umgang mit Emotionen
- 5.2.11 Versorgung von Kindern, jungen Personen und Erwachsenen

=>Case



Case: Simon, Duchenne Muscular Dystrophy I

- Simon, 11.5 years old
- ambulant (north star ambulatory assessment 27 p/34p)
- weight 27.5 kg, height 123.5 cm, normal lung and heart function
- No behavioral problems (5th class in special school disabled children)
- Therapy: physio-, occupational- and speech therapy
- Medication: Cortison, Calcium, Movicol and Ataluren
- Devices: leg brace in the night, wheelchair
- Mother: nurse assistant in a home for elderly, stammering
- Father: 40% logistician, disability pension
- No brothers and sisters
- Grandparents mother side: Austria, good contact; no grandparents father side



Case: Simon, Duchenne Muscular Dystrophy II

- Simon, 16.5 years old
- Non-ambulant (Egen-classification 2 p/51 p)
- Transfer possible (2-3 steps)
- weight 57 kg, height 141 cm
- Lung: little restrictive, heart: normal function (ACE inhibitor)
- Physio- and occupational-therapy
- Medication: Cortison, Calcium, Movicol, Ataluren, ACE-inhibitor and Growth-Hormon
- Devices: now power wheelchair among others
- ... and he has transfered to the adult setting and doing an apprenticeship

Direct Clinical Practice

- Collecting information
- Symptom Management
- **Advanced care planning**
- Clarify and inform
- Guide and instruct
- Counselling and consultation
- Organise and connect
- House calls
- Caregiver support
- Psychosocial support



Living will



Direct Clinical Practice

- Collecting information
- Symptom Management
- Advanced care planning
- Clarify and inform
- Guide and instruct
- **Counselling and consultation**
- Organise and connect
- House calls
- Caregiver support
- Psychosocial support



Counselling



Direct Clinical Practice

- Collecting information
- Symptom Management
- Advanced care planning
- Clarify and inform
- Guide and instruct
- Counselling and consultation
- Organise and connect
- House calls
- **Caregiver support**
- Psychosocial support



Family interview



Interprofessional Collaboration

- Principles of collaboration
- Guiding during therapies and assessments
- Organisation and connectiong
- **Case review, round table discussions, reporting**
- Contact person



Case review

- 5.3 Bereich B: Interprofessionelle Zusammenarbeit im Behandlungsteam
 - 5.3.1 Prinzipien für die Zusammenarbeit
 - 5.3.2 Begleitung bei Therapien, Assessments und erweiterter Diagnostik
 - 5.3.3 Organisation und Vernetzung innerhalb des Behandlungsteams
 - 5.3.4 Fallbesprechungen, Rundtischgespräche und Rapporte
 - 5.3.5 Ansprechperson für Fachpersonen

Professional development and networking

- Professional development
- Networking

5.4 Bereich C: Fachentwicklung und Netzwerkarbeit

5.4.1 Fachentwicklung

5.4.2 Netzwerkarbeit



Overall characteristics of NMD CM

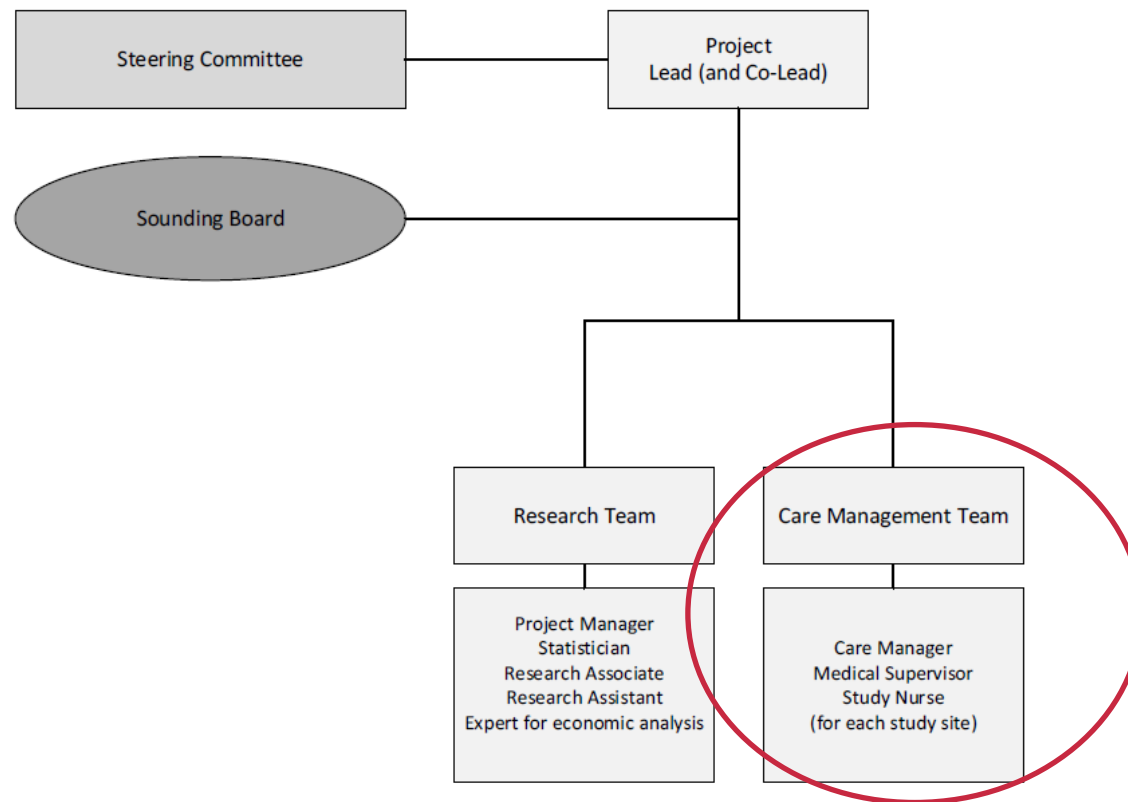
- Having a good overview of the life situation
- Complementary - not competitive
- Close collaboration with patient & family
and with the interprofessional care team
- From novice to expert: Competence development
- Context specific adaptations of the NMD CH concept

Implementation and Evaluation

- Basic education (Kick-off) & regular trainings
- Contact person during implementation (research team, medical supervisor, NMD CM - network)
- Context analysis (data collection in settings, context specific adaptation) -> concept for implementation
- Implementation/ evaluation research: data collection during implementation
 - Document / chart review
 - Interviews / group interviews
 - Online survey

Project organisation

Figure 2: Project Organisation



[illegible]

Time table

Time Table	2022												2023												2024												2025				
	Mar	Apr	May	June	Jul	Aug	Sept	Okt	Nov	Dez	Jan	Feb	Mar	Apr	May	June	Jul	Aug	Sept	Okt	Nov	Dez	Jan	Febr	Mar	Apr	May	June	Jul	Aug	Sept	Okt	Nov	Dez	Jan	Feb	Mar	Apr	May		
	x	x	x	x	x	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	x	x		
Project Management																																									
Project team meetings	x				x		x		x		x		x		x		x		x		x		x		x		x		x		x		x		x						
Sounding Board meeting									x									x							x					x	x			x	x						
Preparation Phase																																									
Proposal developent	x																																								
Application for funding		x	x	x	x																																				
Ethical Application						x	x																																		
Milestone 1: Ethics approval								x																																	
Planning Implementation																																									
Recruitment of Care Manager						x	x	x	x	x																															
Context analysis								x	x	x																															
Planning Education	x		x		x		x		x																																
Education										x			x						x								x														
Networking									x								x								x						x										
Milestone 2: Kick off implementation										x																															
Implementation of Service											x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x					
Implementation Reserach																																									
Data Collection								x	x	x					x	x					x	x					x	x													
Data Analysis								x	x	x						x	x					x	x					x	x												
Writing up																												x	x	x											
Milestone 3: Concept for Implementation																																									
Evaluation Reserach																																									
Data Collection											x	x	x	x	T1 (6M)	x	x	x	x	T2 (12M)	x	x	x	x	T3 (18M)	x	x	x	x	T4 (24M)											
Data Analysis																x	x	x			x	x					x	x	x												
Data integration																																									
Writing up																																									
Milestone 4: Final report																																									
Dissemination																																									
Publications and Presentations																																									

21.03.2022

21.03.2022

Application for Care Management Team

- Online application (Link will be sent) in English
- Project funds up to 4 centres (8 Care Management teams)
- Project funding: approx. 84'000 CHF for each of the 8 Care Management teams (for 2 years)
- Criteria for Committee
- Application deadline: **30.06.2022**
- Information of selection (when more than 8 teams apply) by 31.07.2022

List of criteria for online application

- Motivation for participation
- Description of interprofessional collaboration and integration of Care Manager
- Medical supervisor MS: *Contact details*
- Co-PI (If other than MS) : *Contact details (one Co-PI for each setting required for multicentre study)*
- Care manager(s) CM: *Contact details (if known)*
- Direct superior of CM (if other than MS/PI): *Contact details*
- Concept:
 - Commentary on area A: Direct clinical practice
 - Commentary on area B: Interprofessional collaboration
 - Commentary on area C: Profess. development and networking

List of criteria for online application

- Number of patients (approx. per year/week) (Team)
 - Time / availability of Care Manager (CM)
 - Cover during vacation / sick leave for CM
 - Job description available for CM
 - Preparedness for supporting data collection (Team)
 - Preparedness for attending education / training (CM)
 - Description of collaboration between paediatric and adult care
 - Motivation to collaborate with patient organisations
 - Commentary on financing (not covered budget / in long-term)
 - Formal Application
 - Baseline data available (available to ZHAW)
- > Contact Person in June/July for questions to the committee**



Questions?



Literature 1/2

Amato, A. A., & Russell, J. A. (2008). *Neuromuscular disorders*. McGraw Hill Professional.

Birnkrant, D. J., Bushby, K., Bann, C. M., Alman, B. A., Apkon, S. D., Blackwell, A., Case, L. E., Cripe, L., Hadjiyannakis, S., Olson, A. K., Sheehan, D. W., Bolen, J., Weber, D. R., & Ward, L. M. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. *The Lancet Neurology*, 17(4), 347-361. [https://doi.org/https://doi.org/10.1016/S1474-4422\(18\)30025-5](https://doi.org/https://doi.org/10.1016/S1474-4422(18)30025-5)

Birnkrant, D. J., Bushby, K., Bann, C. M., Apkon, S. D., Blackwell, A., Brumbaugh, D., Case, L. E., Clemens, P. R., Hadjiyannakis, S., Pandya, S., Street, N., Tomezsko, J., Wagner, K. R., Ward, L. M., & Weber, D. R. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *The Lancet Neurology*, 17(3), 251-267. [https://doi.org/https://doi.org/10.1016/S1474-4422\(18\)30024-3](https://doi.org/https://doi.org/10.1016/S1474-4422(18)30024-3)

Birnkrant, D. J., Bushby, K., Bann, C. M., Apkon, S. D., Blackwell, A., Colvin, M. K., Cripe, L., Herron, A. R., Kennedy, A., Kinnett, K., Naprawa, J., Noritz, G., Poysky, J., Street, N., Trout, C. J., Weber, D. R., & Ward, L. M. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *The Lancet Neurology*, 17(5), 445-455. [https://doi.org/https://doi.org/10.1016/S1474-4422\(18\)30026-7](https://doi.org/https://doi.org/10.1016/S1474-4422(18)30026-7)

Elliott, E. J., & Zuryski, Y. A. (2015). *Rare diseases are a “common” problem for clinicians* (Vol. 44). Royal Australian College of General Practitioners. <https://doi.org/10.3316/informit.512019547619809>

Glasson, J. B., Chang, E. M., & Bidewell, J. W. (2008). The value of participatory action research in clinical nursing practice. *International Journal of Nursing Practice*, 14(1), 34-39. <https://doi.org/https://doi.org/10.1111/j.1440-172X.2007.00665.x>

Literature 2/2

Schieppati, A., Henter, J. I., Daina, E., & Aperia, A. (2008). Why rare diseases are an important medical and social issue. *Lancet*, 371(9629), 2039-2041. [https://doi.org/10.1016/s0140-6736\(08\)60872-7](https://doi.org/10.1016/s0140-6736(08)60872-7)

Silverman, B., Cara, M., Boulet, S., & O'Leary, L. (2007). *Logic models for planning and evaluation* https://stacks.cdc.gov/view/cdc/11569/cdc_11569_DS1.pdf

Wang, C. H., Finkel, R. S., Bertini, E. S., Schroth, M., Simonds, A., Wong, B., Aloysius, A., Morrison, L., Main, M., Crawford, T. O., & Trella, A. (2007). Consensus Statement for Standard of Care in Spinal Muscular Atrophy. *Journal of Child Neurology*, 22(8), 1027-1049. <https://doi.org/10.1177/0883073807305788>

Waldboth, V., Hediger, H., Nemecek, G., Fröhli, R., Mezger, M., & Schubert, M. (2021). *Eine Untersuchung der Versorgungssituation von Menschen mit neuromuskulären Erkrankungen in der Schweiz (Projekt Care-NMD-CH) Kurzbericht Phase A: Analyse der aktuellen Versorgungssituation*. Zurich University of Applied Sciences (ZHAW). Retrieved 29.03.2022 from <https://www.zhaw.ch/storage/gesundheit/forschung/fe-pflege/20221121-care-nmd-ch-kurzbericht-phase1-zhaw-gesundheit.pdf>

Waldboth, V., Nemecek, G., Bruschini, M., Hediger, H., Schuler, C., & Schubert, M. (2022). *Konzept für das NMD Care Management Projekt CARE-NMD-CH: Phase B*. Zurich University of Applied Sciences. Retrieved 29.03.2022 from <https://www.zhaw.ch/storage/gesundheit/forschung/fe-pflege/20220323-care-nmd-ch-konzept-final-zhaw-gesundheit..pdf>