REHABILITATION FOR ADULTS WITH CEREBRAL PALSY

Comprehensive project report - Appendices

Hammel Neurorehabilitation and Research Centre

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Appendix 1: Method used to collect and summarize clinical experiences

This section describes the method used for collecting and summarizing clinical experiences in Chapter 3.

The process was guided by a conceptual framework[1,2] that identifies factors influencing the use of healthcare services.

The collection of clinical experiences followed a structured process:

Workshop: The clinical staff participated in a workshop where they wrote down their experiences as key points on post-its and categorized them within the conceptual framework displayed on the wall.

Working meetings: After the workshop, the clinical staff took part in working meetings, where they collaboratively expanded and clarified their experiences in a word document.

Summary and consensus: The collected material was structured by an academic staff member based on the conceptual framework.[1,2] The initial structuring of experiences was caried out using NotebookLM as an analytical support tool. NotebookLM is a generative AI tool that generates output based on the user's prompts and the material the user has uploaded.[3] Only anonymised information was prompted in NotebookLM.

Consensus on the summary was reached through weekly meetings with the clinical staff in November and December 2025.

This method ensured a systematic collection and processing of experiences, which formed the basis for the subsequent recommendations.

References

1. Lederle M, Tempes J, Bitzer EM. Application of Andersen's behavioural model of health services use: a scoping review with a focus on qualitative health services research. BMJ Open 2021; 11(5): e045018.

2. Andersen RM, Davidson PL, Baumeister SE. Chapter 2: Improving access to care. In: Kominski GF, ed. Changing the US health care system: key issues in health services policy and management. United States: John Wiley & Sons; 2013: 33-69.

3. Google. NotebookLM (Nov 2025 version) [Large language model]. 2025. https://notebooklm.google/.

Appendix 2: Treatment with Botulinum Toxin in the project

The project includes treatment with botulinum toxin (BTX) when this is assessed as clinically relevant. Eligibility for treatment is determined on the basis of a physical examination conducted jointly by a physician and a physiotherapist.

In cases where muscle overactivity is identified, an assessment is made of whether there is a clinical indication for treatment, with particular emphasis on the impact of muscle overactivity on the individual's daily functioning (for example pain, limitations in activity or participation). When an indication is established, treatment with BTX is initiated.

Some participants may already be receiving BTX treatment prior to inclusion in the project. If there is a need to test or adjust the existing treatment regimen, the relevant hospital is contacted. In many cases, an agreement can be made for the treatment to be temporarily transferred to the project for a defined period, after which responsibility for treatment is returned to the original provider.

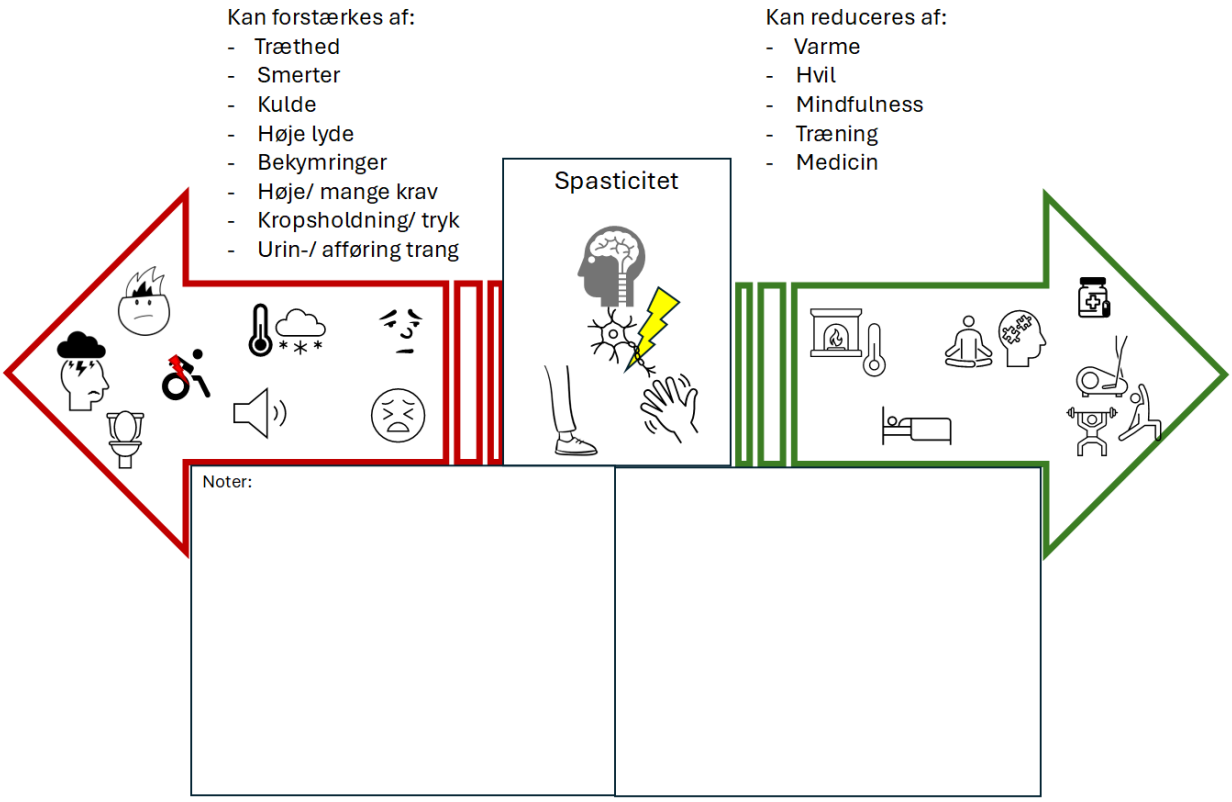
At initiation of treatment, individualized treatment goals are defined, and baseline assessments are conducted. Baseline measures are selected based on the clinical indication and may include joint range of motion, degree of muscle overactivity, balance assessments, hand function tests, and pain measures.

BTX is administered at three-month intervals. A follow-up assessment is conducted approximately four weeks after each treatment session. During follow-up, selected baseline measures are repeated, and, based on the assessment results and clinical dialogue with the participant, a plan for subsequent treatment is developed.

Treatment is delivered by a multidisciplinary team consisting of a physician, a nurse, and a physiotherapist. Each treatment session lasts approximately 30–60 minutes and is performed under ultrasound guidance. Follow-up assessments are conducted by a physician and a physiotherapist and typically last approximately 30 minutes. A fixed weekday is currently allocated for treatment and follow-up appointments. Scheduling of participants is managed by the team secretary.

When an optimal and stable treatment plan has been achieved, the participant is referred to the nearest hospital for continuation of treatment outside the project setting.

Example of teaching material for spasticity following treatment



Appendix 3: Outpatient clinic and the interdisciplinary team

Outpatient clinic

People who are referred to a patient pathway in the CP clinic are offered clinical evaluation through outpatient appointments in the clinic's outpatient department. The pathway begins with an initial meeting, after which the interdisciplinary clinical evaluation of the user's needs continues through planned follow-up appointments in the outpatient clinic.

Initial meeting

Before the initial meeting, the user's current needs and municipal services are explored by telephone and through questionnaires, while unmet needs are also clarified. The CP clinic's physician prepares a comprehensive medical history based on the information available in the electronic patient record (EHR). For users who have recently turned eighteen, the evaluation builds on previous assessments from paediatric services.

The initial outpatient appointment with the user and potential relatives is scheduled for approximately 1.5 hours. In some cases, the initial meeting takes place as a video consultation, for example if the user is assessed as too fragile to attend a physical appointment. The meeting is attended by the physician, physiotherapist, occupational therapist, and nurse from the interdisciplinary team. The conversation in the initial meeting is based on the user's responses to the questionnaire with self-evaluations and the user's goals for the patient pathway. Relatives often contribute additional information if they are able to attend.

Current municipal interventions are explored as part of the first contact and needs assessment. Clinical examinations take the form of an overall screening and may address neurological issues as well as other factors affecting activity and participation in daily life.

Clinical evaluation of needs with the user in the outpatient clinic:
The interdisciplinary CP team, consisting of a physician, physiotherapist, occupational therapist, nurse, neuropsychologist, speech and language therapist, and social worker, handles the clinical evaluation of clinical evaluation of needs with the user in the outpatient clinic.

The interdisciplinary evaluation in the outpatient clinic is based on individual issues and needs using the ICF framework. Specifically, this approach includes assessment at the levels of body function, activity, and participation. The holistic approach in the evaluation is carried forward into subsequent actions and planning in collaboration with the user, relatives, and relevant municipal stakeholders.

Clinical evaluation and follow-up with the user may be carried out through repeated outpatient appointments and video consultations, which are often supplemented by one or two home visits. In some cases, it may also be relevant to include visits to workplaces or educational institutions, meetings with assistive-technology suppliers, and meetings with municipal stakeholders in the user's home.

The outpatient appointments may take place in the clinic's examination rooms, training/workout room, training kitchen, or training apartment.

As a supplement to outpatient appointments, users are offered telephone or email contact with a designated contact person in the team, who can coordinate and provide an overview of the pathway. This often involves close collaboration with the user's municipal contact person, if one is assigned, so that both parties can evaluate whether planned interventions have been initiated and what may be needed to support them.

Coordination and follow-up:
During the initial contact, it is clarified whether a designated municipal coordinator exists and whether this person may exchange information about the user's pathway with the CP clinic. This allows for direct communication with a local professional who possess knowledge of ongoing municipal interventions, ensuring that outpatient appointments and potential inpatient admissions can complement and support these.

Coordinating meetings may be offered between the user, relatives, professionals from the CP clinic, the GP, private physiotherapy practitioner, residential-facility staff, employers, or other relevant stakeholders.

Options for cross-sector collaboration may include:

- Coordinating meetings.
- Written communication in the form of an interdisciplinary status report on human functioning.
- Telephone or virtual follow-up

Data collection
As part of the outpatient service, data from the patient medical record and questionnaires are collected to monitor the user over time and to increase knowledge about the target group, thereby providing a foundation for quality assurance and research into the effects of interventions.

Interdisciplinary team

The interventions in the project are never carried out monodisciplinarily. Instead, patient pathways are coordinated within interdisciplinary processes involving the adult with CP, relatives, professionals, personal care assistants, and others.

Professional role	Examples of tasks and interventions
Projekt lead	• Daily clinical coordination. • Overall communication with municipalities, residential facilities, and referring physicians.
Physician ***(37 hours/week)***	• Review of medical records and diagnostic imaging. • Consolidation of medical history. • Assessment of guardianship and ceiling of care. • Medication adjustment and trials. • Pain management and therapy. • Follow-up on epilepsy control. • Assessment of the need for routine follow-ups in the healthcare system. • Referral for surgery and postoperative follow-up consultations. • Coordination with the general practitioner and specialists.

Professional role	Examples of tasks and interventions
	• Referral for examinations such as X-ray of hip/knee, CT and MRI of the cerebrum, MRI, neurophysiological investigations, and investigation for kidney stones. • Consultations and communication with users, relatives, and, for example, municipalities or residential facilities regarding CP and clinical evaluations/interventions in the pathway.
Neuropsychologist ***(26 hours/week)***	• Observations and cognitive screening, with supplementary questionnaires for relatives and contact persons. • Recommendations for support and communication. • Conversations about symptoms of strain and well-being factors. • Communication about how CP affects the brain in relation to cognition, behaviour, and sensory processing.
Occupational therapists ***(37 hours/week and 32 hours/week, respectively)***	• Evaluation and guidance regarding daily activities, activity balance, and activity performance. • Observation and assessment of motor and process skills relevant to activities. • Guidance on compensatory strategies, including assistive devices and environmental adaptations. • Assessment and psychoeducation about fatigue and energy-management strategies. • Assessment of sensory processing using sensory profiles. • Focus on social relationships and social participation, including development of social-network maps. • Assessment of dysphagia and guidance on mealtime adjustments (for example positioning, food consistency). • Collaboration with the user's network, relatives, personal care assistants, and residential facilities.
Physiotherapists ***(35 hours/week and 32 hours/week, respectively)***	• Assessment of walking ability, mobility, and transfers. • Assessment of spasticity, bodily joint, and postures. • Adjustment of wheelchair seating and positioning. • Guidance to users, relatives, and assistants on positioning and ergonomics. • Applications for assistive devices. • Conversations and counselling on daily life with CP, physical activity, and training. • Advice and professional sparring to physiotherapists providing free of charge physiotherapy, municipal assessors, and assistive device teams.
Speech and language therapist ***(10 hours/week)***	• Observation of communication. • Development of communication strategies. • Guidance for professionals. • Assessment of the need for and use of communication aids. • Guidance for users on energy-management strategies related to communication.
Nurses ***(37 hours/week and 19.5***	• Systematic registration of pain, incontinence, nutrition, toileting patterns, and agitated behaviour.

Professional role	Examples of tasks and interventions
hours/week, respectively)	• Planning of interventions, including how these relate to overall human functioning in daily life (for example participation in social activities). • Overview of health appointments and interventions. • Conversations and guidance about health-related behaviour and everyday routines. • Conversations about support needs in daily life. • Coordinating communication and collaboration with municipalities.
Social worker ***(7.5 hours/week)***	• Assessment and guidance regarding financial situation, unmet support and assistance needs, and available options. • Contact to municipality regarding applications for disability pension, compensation benefits, coping skills advisor, housing support services, and other support options. • Arrange and participate in meetings with the municipality. • Advise relatives on guardianship • Assist with application with the Family Court Agency.
Project secretary ***(20 hours/week)***	• Processing of incoming referrals. • Scheduling and booking patient appointments. • Transcription of notes into the medical record- • Preparation of certificates. • Referrals to other services. • Patient communication. • General administrative tasks.

Appendix 4: Interdisciplinary status template

Tværfaglig status – vejledning.

Markering med **fed skrift** markerer overskrifter.
Kursivtekst er vejledning ift. hvad der skal stå under de enkelte overskrifter.
Standardformulering står med almindelig skrifttype.
BLOKBOGSTAVER indikerer, at der skal indsættes relevante oplysninger.
Skrifttype: Times New Roman.

FULDE NAVN er set i forbindelse med et tværfagligt rehabiliteringstilbud for voksne med cerebral parese. *Noter herefter gerne hvornår forløbet er opstartet og afsluttet.*
Noter hvordan forløbet har været opbygget fx hjemmebesøg, ambulatorie besøg, online møder, indlæggelse, gruppeforløb.
Noter hvilke faggrupper teamet har bestået af.
Noter evt. grad af deltagelse fra omgivelser - forældre, bostøtte mv. Fx: det har været afgørende for forløbet at Peters forældre har deltaget aktivt idet Peter har behov for støtte til at .....

Baggrund/kort beskrivelse
Oprids i korte træk hvem personen er samt livssituation fx "Peter er en 35- årig mand med cerebral parese som bor i egen bolig. Han får hjælp af hjemmeplejen morgen og aften. Peter modtager førtidspension.

Lægefaglig status
Lægefaglig beskrivelse, der indeholder diagnose og kort funktionsbeskrivelse med afsæt i ICF. Team kan supplere ved behov.

Der er i forløbet udarbejdet sygdomshistorik ????
Blodprøver?
Røngten?
Scanning?

I forlængelse af epikrise:
Som standard er der udført blodtryksmåling: Hø. arm:..... Ve. arm:.....
(noter evt. opfølgning ved egen læge)

Ønsker og mål for forløbet/årsag til deltagelse i projektet
Kort beskrivelse af ønsker og mål, evt. problemstillinger – angivet af personen selv og/eller omgivelserne. Hvis dette ikke er tilgængeligt, noteres teamets vurdering. Hvis der er inkongruens mellem personens ønsker og mål og teamets, noteres dette.

Fokusområder
Kort beskrivelse af fokusområderne der er arbejdet med, gerne i punktformer.
Fx kognitiv funktion, gangfunktion mm.

Vigtige fund samt indsatser

Selvrapporteret funktionsevne og livskvalitet: Indsæt WHODAS 2.0, EuroQuol (EQ-5D-5L), MFI-20, MIC-SR.*
Kort opsummering af de vigtigste fund. Kan inddeles i underskrifter fx.
NAVN's hverdag (herunder hverdagsrutiner, interesser, aktivitetsniveau, grad af støtte/selvhjulpenhed)
Socialt – familie og netværk
Fysisk funktion
Håndfunktion
Hverdagsfærdigheder
Psykisk funktion/mentalt helbred
Udtrætning og energiforvaltning (indsæt evt MFI-20 her)
Livsfase/transitioner (fx ungdomsliv, seniortilværelse) se afsnittet: "til inspiration".
Udskillelse
Ernæring
Kognition
Bevilget hjælp og støtte (herunder afslag)
Kommunikation (herunder læse og skrive færdigheder, brug af hjælpemidler)
Indsatser noteres i relation til hvert område.

Anbefalinger på baggrund af forløbet
De vigtigste anbefalinger og opmærksomhed fremadrettet beskrives kort. Se forslag til standardtekster nederst.

Afslutning
Ovenstående fund er formidlet mundtligt og skriftligt til NAVN, pårørende og personale.
Uddybende dokumenter kan rekvireres ved behov, med samtykke fra NAVN.
Ved personer med CP der har lavt funktionsniveau er det relevant at notere om personen deltog i formidlingen. Såfremt personen ikke deltog begrund da hvorfor, fx grundet lavt kognitivt niveau har det ikke været hensigtsmæssigt at formidle fundene til personen.

***Selvrapporteret funktionsevne og livskvalitet**
Selvrapporteret funktionsevnenedsættelse
[NAVN] har rapporteret funktionsevnenedsættelse med WHO's Disability Assessment Schedule (WHODAS 2.0) med en funktionsevnenedsættelse på xx% svarende til en ingen, mild, alvorlig, moderat, alvorlig funktionsevnenedsættelse.

Selvrapporteret livskvalitet
Helbredsrelateret livskvalitet vurderet med EuroQuol (EQ-5D-5L). [NAVN] rapporterer index-værdi på X,XXX svarende til meget dårlig, dårlig, moderat, god, fremragende helbredsrelateret livskvalitet.

Selvrapporteret træthed (fatique)
[NAVN] har med Multi-dimensional Fatigue Inventory (MFI-20) angivet en samlet fatigue på xx%, samt en oplevelse af generel træthed på patologisk niveau.

Selvrapporteret kognitiv funktion
Selvopfattet kognitiv funktion er vurderet med Meta-Cognition Inventory for Self-Report (MIC-SR), hvor der indgår vurdering af opmærksomhed, hukommelse og eksekutive funktioner. [NAVN] har rapporteret en total MIC-SR-score på XX ud af 36 mulige.

Vigtigste fund samt indsatser til inspiration:

At være ung med CP
NAVN er en ung kvinde med CP. Overgangen fra ung til voksen er en krævende livsfase med mange beslutninger og udfordringer. At prøve sig selv af i forskellige sammenhænge er både nødvendigt og energikrævende. NAVN får støtte fra familie og personale på bostedet, især i forbindelse med deltagelse i møder og beslutningsprocesser, hvilket kan være svært for hende.
NAVN har mange drømme, herunder at være ung uden funktionsevnenedsættelse, at kunne bevæge sig frit omkring, samt at tage sin drømmeuddannelse som sygeplejerske. NAVN kan i perioder være følelsesmæssigt påvirket af sine begrænsninger og har behov for samtaler med familie eller kontaktpersoner på botilbuddet. NAVN har også kontakt til en psykolog, som hun kan opsøge ved behov.
Denne følelsesmæssige påvirkning og behovet for at sammenligne sig med andre unge uden funktionsevnenedsættelse er en naturlig del af ungdomslivet, som dog kan medføre usikkerhed og påvirke selvværdet. NAVN har i perioder, hvor hun trives, gode mestringsstrategier. Det vil dog være forventeligt, at der er behov for tæt støtte i processen.

Anbefalinger
Forslag til standardtekster, der kan tilrettes og kopieres ind:

Svingende funktionsevne
Det er forventeligt at funktionsevnen vil være svingende i løbet af dagen og ugen grundet den cerebrale parese, og der bør derfor tages hensyn til dette i hverdagen.

Energiforvaltning
Det anbefales at have fokus på energiforvaltning med henblik på at opnå/bevare en passende balance mellem basale hverdagsaktiviteter, pauser/hvile, meningsfulde aktiviteter, sociale aktiviteter mv. ud fra egne ønsker og behov.

Fysisk aktivitet
Det anbefales at have fokus på fysisk aktivitet i hverdagen med henblik på at forebygge negative konsekvenser som følge af inaktivitet. Her vil det være vigtigt at tilpasse aktiviteterne i overensstemmelse med motivation, ønsker og behov.
Den fysiske træning kan bidrage til øget mentalt og fysisk overskud i hverdagen og det anbefales derfor at træningen prioriteres, som en vigtig del af de ugentlige aktiviteter. Det vil være en fordel at træningen foregår på tidspunkter, hvor NAVN ikke allerede er udtrættet.

Sundhed

Det anbefales at komme til årligt helbredstjek hos egen læge, som man selv skal bestille tid til. Egen læge kontrollerer blodprøver, vi anbefaler at blodprøven inkluderer D vitamin niveau.
- Det anbefales et livslangt og helårligt tilskud af D vitamin, (antal mikrogram eller blot en tabl. Multivitamin).

Tarmfunktion:
(indsættes hvis det har været et problemområde)
Ved Cerebral Parese ses ofte en kronisk nedsat tarmfunktion, som forværres over tid. Det kan derfor, på et senere tidspunkt, være hensigtsmæssigt med en nærmere udredning i mave- og tarm kirurgisk regi. Dette kan ske i samarbejde med din egen læge.

Aldring
Det er forventeligt at aldersbetingede forandringer vil indtræde tidligere og mere udtalt grundet den cerebrale parese. Derfor anbefales et kontinuerligt fokus på tilpasning af omgivelserne fx i form af hjælpemidler og støtte i hverdagen med henblik på at forebygge mental og fysisk overbelastning.

Ved anbefaling af anden boform/mere støtte
Det vurderes, at der vil være et berettiget omfangsrigt behov for støtte i hverdagslivet til daglig mestring og opretholdelse af rutiner svarende til en boform med personalestøtte hele døgnet. Der vurderes risiko for [NAVN]s sundhed og trivsel, såfremt [NAVN]s funktionsevnenedsættelse ikke understøttes.

Botulinumtoxin og fysisk aktivitet
Det anbefales at NAVN fremadrettet har mulighed for at være fysisk aktiv og at der er fokus på muskelstyrke og bevægelighed, som forudsætning for at kunne medvirke til aktive forflytninger, basale hverdagsfærdigheder samt opretholde en stabil stand- og siddefunktion. Det anbefales at NAVN fortsat modtager behandling med botulinumtoxin mhp. at reducere spasticiteten i begge ben. Denne behandling, i tillæg til træning og fysisk aktivitet, optimerer betingelserne for aktivitet og deltagelse, som beskrevet ovenfor.

Appendix 5: Break-even analysis of clinical pathways

This health-economic evaluation is based exclusively on direct salary costs using standardized Danish hourly rates (600 DKK per hour for consultant physician, 300 DKK per hour for nurse, physiotherapist, occupational therapist and social worker, and 400 DKK per hour for neuropsychologist). Documentation time, infrastructure, and administrative costs are not included.

All pathways (Figure 5 in main document) include **a shared interdisciplinary baseline assessment phase**. This consists of a 30-minute interdisciplinary team meeting (circa 950 DKK), a 90-minute outpatient multidisciplinary assessment visit (circa 2,850 DKK), a one-hour interdisciplinary status conference involving physician, nurse, physiotherapist, occupational therapist and neuropsychologist (circa 1,900 DKK), and a one-hour final evaluation meeting with occupational therapist, physiotherapist and nurse (circa 900 DKK). The total fixed interdisciplinary baseline therefore **amounts to circa 6,600 DKK per patient**, independent of the subsequent pathway.

High-Resource Inpatient Clinical Pathway
The base inpatient episode cost is 56,280 DKK. Additional structured interdisciplinary follow-up components during admission amount to circa 5,000 DKK, group-based interventions to circa 7,200 DKK, and a parallel botulinum toxin cycle to circa 1,800 DKK. Including the shared interdisciplinary baseline of circa 6,600 DKK, **the full inpatient pathway amounts to circa 76,880 DKK per patient**.

Medium-Resource Outpatient Pathway (Botulinum Toxin Example)
This pathway consists of **six one-hour outpatient contacts** attended by physician, nurse and physiotherapist. Each contact costs circa 1,200 DKK, resulting in circa **7,200 DKK** for the pathway-specific component. Including the baseline assessment phase, **the total cost of the medium-resource pathway amounts to circa 13,800 DKK per patient**, corresponding to roughly 18-19 percent of the inpatient reference cost.

Intensified Interdisciplinary Outpatient Pathway
Based on clinical team assessment that approximately eleven structured interdisciplinary outpatient visits may achieve outcomes comparable to inpatient treatment in selected patients, this pathway includes **eleven one-hour contacts** with physician, nurse, physiotherapist and occupational therapist. Each visit costs circa 1,500 DKK, resulting in circa 16,500 DKK for the pathway-specific component. Including the interdisciplinary assessment phase, the **total cost amounts to circa 23,100 DKK per patient**, corresponding to about 30 percent of inpatient costs.

Low-Resource Pathway (Primarily Telemedicine)
Even when including the fixed interdisciplinary baseline of circa 6,600 DKK, **total costs typically remain below circa 7,800 DKK per patient**, depending on the number and duration of teleconsultations.

Break-Even Analysis

Using the full inpatient pathway of circa 76,880 DKK as benchmark, one inpatient case corresponds economically to approximately five to six medium-resource outpatient pathways or roughly three intensified outpatient alternatives. Even when a full interdisciplinary assessment, status conference and final evaluation are systematically included in all pathways, structured outpatient care remains substantially less costly than inpatient admission.

Appendix 6: Outline for research plan

The research plan has been omitted from the present version due to ongoing and future grant applications. An outline is available upon reasonable request. Please find the contact information in the imprint for the project report.