

# Network Activeoncokids – Centralized Physical Activity Counseling for Children, adolescents, and Young Adults Across German-Speaking Countries Throughout All Oncological Treatment Phases

## Netzwerk ActiveOncoKids – Zentralisierte Sportberatung im deutschsprachigen Raum für Kinder, Jugendliche und junge Erwachsene in allen onkologischen Behandlungsphasen



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### ABSTRACT

Reaching age-appropriate physical activity levels is a significant challenge for many children, adolescents, and young adults (CAYAs) with and following an oncological disease. Many CAYAs require support in addressing physical activity-specific questions and need assistance in accessing sports and exercise offers in their local area. Since many clinics cannot provide such time-intensive counseling, the nationwide operating network ActiveOncoKids (NAOK), funded by the German Cancer Aid, offers individualized support to participate in physical activity (PA). This paper describes the NAOK-Physical-Activity-Counseling (-PAC) concept and evaluates the initial 200 consultations, focusing on recruitment, objectives, and oncology-specific parameters. Ultimately, dimensions of barriers and facilitators and intervention options are discussed.

### ZUSAMMENFASSUNG

Das Erreichen altersgerechter körperlicher Aktivitätsniveaus stellt für viele Kinder, Jugendliche und junge Erwachsene (CAYAs) mit und nach einer onkologischen Erkrankung eine bedeutende Herausforderung dar. Viele CAYAs benötigen Unterstützung bei der Bewältigung spezifischer Fragen zur körperlichen Aktivität und Unterstützung beim Zugang zu heimatnahen Sport- und Bewegungsangeboten. Da viele Kinderonkologische Zentren eine solch zeitintensive Beratung nicht leisten können, bietet das bundesweit tätige Netzwerk ActiveOncoKids (NAOK), finanziert

durch die Deutsche Krebshilfe, individuelle Unterstützung zur Teilnahme an körperlicher Aktivität (PA) an. Dieser Artikel beschreibt das NAOK-Sportberatungs (-PAC) Konzept und evaluiert die ersten 200 Beratungen, wobei der Fokus auf Rekrutierung,

Zielen und onkologiespezifischen Parametern liegt. Abschließend werden Dimensionen von Barrieren und Förderfaktoren sowie Interventionsmöglichkeiten diskutiert.

## ABBREVIATIONS

<b>CAYAs</b>	Children, adolescents, and young adults
<b>PA</b>	Physical activity
<b>HQ</b>	Headquarter
<b>PAC</b>	Physical-Activity-Counseling
<b>LLE</b>	Late and long-term effects
<b>PE</b>	Physical Education
<b>NAOK</b>	Network ActiveOncoKids
<b>POC</b>	Pediatric oncology centers

## Background

The medical guideline on the promotion of physical activity (PA) and exercise in pediatric oncology emphasizes the necessity to implement the “National Recommendations for Physical Activity” for affected children, adolescents, and young adults (CAYAs) as its primary recommendation [1]. Despite an increasing number of exercise initiatives at pediatric oncology centers (POC), most local structures are currently not including a comprehensive Physical-Activity-Counseling (PAC) service tailored to the individual needs (in-/outpatient, at home, during follow-up and survivorship, in palliative care). In Germany, about 2,200 children and adolescents aged < 18 years are newly diagnosed with an oncological-hematological disease annually [2]. Despite 5-year survival rates exceeding >80% [3], cancer suddenly and permanently changes the lives of CAYAs. The disease and medical therapy are affecting the entire family system, including high psychological burden and unexpected organizational, financial, and bureaucratic hurdles [4]. Newly diagnosed young adults, planning their future, including career entry, partnership, autonomy and possibly the desire to family formation, are facing the fight against a life-threatening disease, with late and long-term effects (LLE) often persisting throughout adulthood.

Many patients suffer from common side effects, repeating inpatient stays and protracted hospitalization resulting in a reduced quality of life [5], limited social activities and school attendance [6] as well as reduced cardiopulmonary fitness [7], and muscle strength [8]. After cessation of treatment, some patients suffer from LLE such as weight changes [9], polyneuropathies [10], osteonecrosis [11], balance disorders [12], and movement restrictions due to prosthetic devices [13] or fatigue [1]. They show a lower level of fitness and health during follow-up compared to healthy peers [14–16]. An adapted exercise programme can also positively influence all phases of therapy and counteract lacks of physical-mental resilience and performance. Targeted exercise interventions have the potential to reduce negative impact of physical inactivity on health and to support age-appropriate development of physical and

coordination skills and social and sports participation. Thus, optimal conditions to return to former (sports) structures or, if necessary, to access new adapted PA programme through positive exercise experiences adapted to LLE are provided.

Therefore, many POC strive to implement exercise programme, including counseling from diagnosis onward. In Germany, 33 POC (55%) currently offer exercise of varying extents, which are bundled at the Network ActiveOncoKids (NAOK) headquarters (HQ; [17]). However, the majority of patients still do not receive supervised exercise interventions or support in practices of daily life, such as q.e. cycling [18]. Families, coaches and physical education teachers however are not qualified to take on this role. Situations like inexperience regarding exercise pre-diagnosis, social disadvantages and/or severe psychological burden, an unsupportive social environment, rural surroundings or complex LLE might require particularly intense support. The NAOK [17] was founded to especially empower these groups to participate in PA programme and to support POC in establishing an exercise and counseling programme for all CAYAs throughout Germany. Since 2019, NAOK-HQ has been focusing on raising awareness of the relevance and prospect of its POC in a multidisciplinary team, and on implementing and evaluating exercise as effectively as possible. In addition to counseling, the NAOK-HQ and the NAOK steering group are in charge of structural and scientific topics such as writing medical guidelines [1], clinical consultations and public relations [17]. In 2019, NAOK has been established as working group with statutes and membership applications within the German medical Society for Pediatric Oncology and Hematology.

This article describes the NAOK-PAC concept, its development and the first 200 included CAYAs patients and survivors.

## Aims and structure of physical activity counseling (PAC)

The NAOK-PAC addresses CAYAs with all cancer diagnoses and ages and their families to find available and accessible PA programme. The underlying principle of the counselling is an individualised approach, taking account of local circumstances and involving local coaches and sport clubs if appropriate. Oncology-specific PA projects, such as post-amputation or transplantation activity events are arranged. Another focus is on (re)integration into Physical Education (PE).

## Contacting the network ActiveOncoKids (NAOK)

The NAOK-HQ promotes the PAC in three ways: (1) proactive contact, (2) medical staff contact, and (3) event-based contact. Contact attempts refer to all individuals who have directly contacted the NAOK-HQ (1). This includes the homepage (<https://www.activeoncokids.de/>), links to associated websites (e. g., German Cancer Aid; Kinderkrebsinfo), social media (Instagram, Facebook) and print materials available at clinics:

- Training booklet “Let’s go” (QR code; 1)



QR code Training booklet "Let's go" (QR code; 1); <https://www.activeoncokids.org/betroffene/trainingsbroschuere-des-naok/>,  
Quelle: Netzwerk ActiveOncoKids, <https://www.activeoncokids.org> [rerif]



QR code Leaflet for patients and multidisciplinary teams (QR code; 2); <https://www.activeoncokids.org/neue-naok-flyer/>,  
Quelle: Netzwerk ActiveOncoKids, <https://www.activeoncokids.org> [rerif]

- Leaflet for patients and multidisciplinary teams (QR code; 2)

Another way of connecting to the NAOK-PAC is via local clinic staff aware of the NAOK (2). A POC can contact the NAOK-HQ via phone, e-mail, or in person. A third option is the presence of the NAOK-HQ at events (3) (e. g., meetings of the NAOK, nationwide camps, seminars, self-help groups).

### Further developments

After a decrease in contact requests during the COVID-19 pandemic, its number has been growing steadily, using social media channels and new print materials, and showing a strong increase upon attending patient events. After personal contact with a clinic's multidisciplinary team, the number of inquiries increases, as the providers actively recommend NAOK-PAC.

## Material und Methods

### Description of the NAOK physical activity counseling concept

The NAOK-HQ uses a consulting model (► **Fig. 1**) that is being continuously developed as an agile system concept based on the growing experience gained in NAOK consultations. It includes the following five phases: preparation, anamnesis, organization, test phase, and feedback. At three measurement points ( $t_0$  = anamnesis;  $t_1$  = after four weeks;  $t_2$  = after 16 weeks), data is collected on goal setting and completion as well as on subjective perception of exhaustion and stress.

#### Phase 1 – Preparation

An appointment-based telephone or in person meeting is held. If contact is made through a parent, the person concerned also takes part in the meeting. Children aged > 8 years are always participating. At the beginning, information is provided on the structure of the NAOK including the funding by the German Cancer Aid, data protection and the joint working basis. The objective of the latter is not to

meet new requirements as participation in the programme is entirely voluntary and is primarily based on the patient's needs [19].

#### Phase 2 – Anamnesis

The anamnesis includes six categories:

1. Basic data,
2. Disease-specific data,
3. Exercise-specific data,
4. Objectives and needs of the CAYAs
5. Subjective evaluation of physical/mental exhaustion and resilience at three measurement points ( $t_0$ - $t_2$ ; since consultation no. 151).

If appropriate, patients are asked to record a video, showing them in action (e. g., gait after prosthetic fitting, balance status after brain tumor, severity of hemiparesis, degree of obesity), and to provide the medical letter.

→ The QR code links to the anamnesis questionnaire.



The QR code 3 links to the anamnesis questionnaire; <https://www.activeoncokids.org/naok-sports-advice-questionnaire/>,  
Quelle: Netzwerk ActiveOncoKids, <https://www.activeoncokids.org> [rerif]

### KEY MESSAGE

During the assessment, possible sports are weighed up as to risks and benefits and logistic aspects (accessibility, time required, personal requirements) are addressed [20].

#### Phase 3 – Organization

In the organization phase the aims identified by CAYAs (and parents) are considered individually and approaches to participation in PA programme are presented. The pre-collected information on a structural and personal level as well as the cooperation partners (► **Fig. 1**) is integrated. Soon after the anamnesis, all parties involved receive an e-mail, summarizing the discussion, formulating the next steps taken by the advisor and providing basic information (social media, general training recommendations, empirical education projects suitable for the target group, etc.). A follow-up email offers targeted and individualized exercise programme, includes a request to review the PA programme, and prompts feedback on what recipients consider interesting and relevant. There are three different organization phase procedures, depending on the setting of the chosen PA.

#### Procedure in the setting of sports clubs: Strengthening of self-confidence, social skills, and physical health

- Contacting the sports club.
- Involving local NAOK clinics and NAOK members' experience.
- Contacting coaches of appropriate groups.



► **Fig. 1** Cooperation partners and supporters of the NAOK; the colors were chosen arbitrarily, Quelle: Netzwerk ActiveOncoKids, <https://www.activeoncokids.org>. [rerif].

- Checking whether the offer, the pedagogical concept, and the group performance level matches the needs.
- Arranging a test training.
- Informing the coaches on any possible experience, restrictions, and the NAOK's support.

#### Procedure in the PE setting: Participation of participation and ensuring weekly physical activity session

- Involving the parents, an online meeting is scheduled with the invited PE teacher to discuss (re)integration into PE, with the option for the parents to join or not.
- Including NAOK expert on PE issues.
- Examination of the problem from all perspectives.
- Developing solutions jointly, e. g., teacher training, providing relevant information brochures, involving expert staff who promote inclusion or specific sports recommendations from the medical doctors.

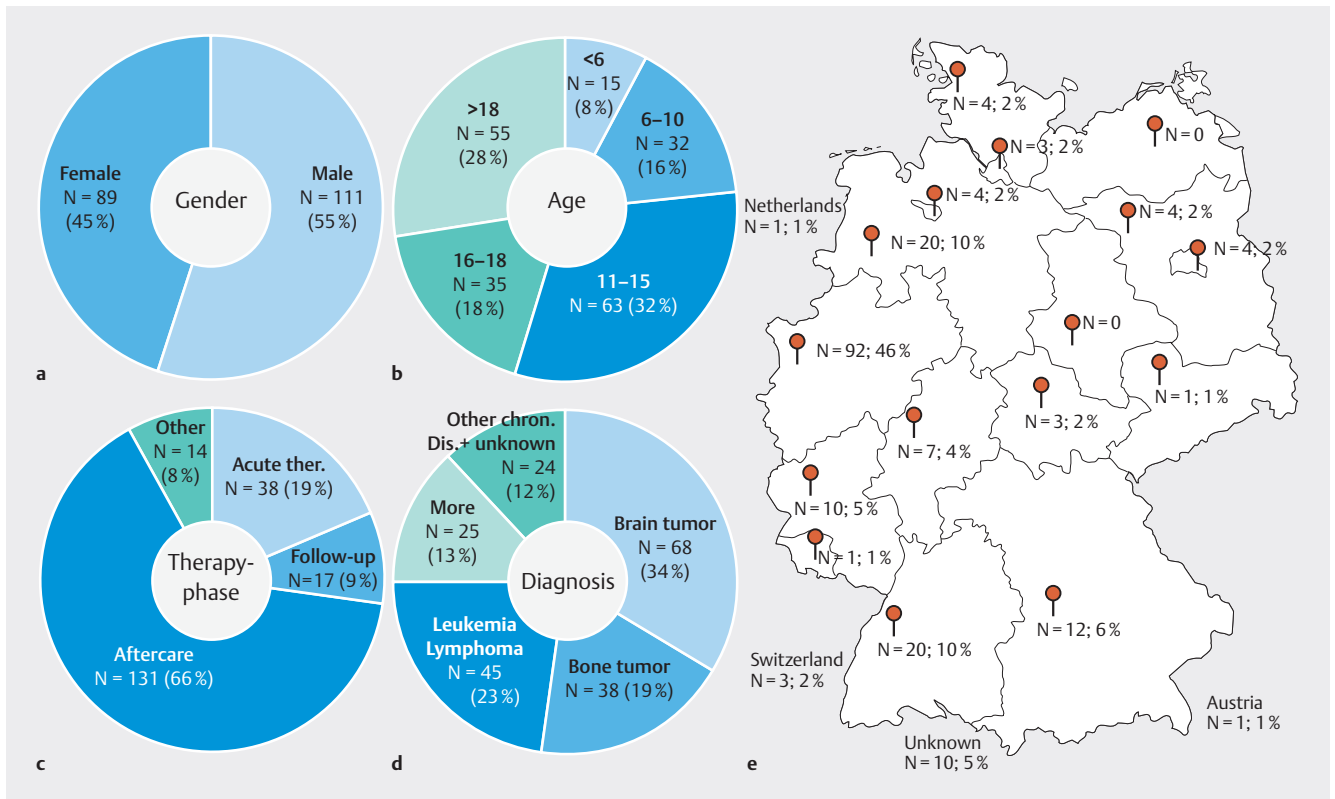
#### Procedure for cross-setting goals: Mitigating LLE of medical therapy and participation as well as increasing self-efficacy

- Organizing, e. g., horse riding therapy, swimming courses, personal training, physio- or occupational therapy.
- Involving foundations/associations in case of family's financial overload.

- Creating individualized training programme by the NAOK-HQ.
- Establishing contacts and offering education to exercise therapists by the NAOK-HQ.
- On request, psychosocial support of exchange with other affected persons and experts, establishment and expansion of self-help groups, advice platforms.
- Improving everyday mobility, e. g., by providing opportunities to attempt barrier-free cycling and receive tailored consultation from NAOK members.
- Notice the offers of NAOK centers (Ruhr, North, Bavaria, Rhine-Main-Neckar, central Germany), the internal NAOK clinics, and other cooperating partners and institutions.
- Communicating information access points (homepage, flyers, etc.) and contact persons.

#### Phase 4 – Test phase

During the test phase, those CAYAs become familiar with the sports programme without obligation, implement the ideas developed, test the infrastructural situation for feasibility as well as compare general conditions (group size and composition) and the objectives with their own needs. Depending on the availability of the contact person at the home location and the implementation options to be advised, a few days to several weeks can pass between the initial meeting and the start of the test phase.



► **Fig. 2** Characteristics of gender (a), age (b), therapy phase (c), diagnosis (d) and localization (e) at the time of the initial contact (Abbreviations used: “Other cron. Dis. – Other chronic diseases”; Acute ther. – Acute therapy”).

## Phase 5 – Feedback

Both after four ( $t_1$ ), 16 weeks ( $t_2$ ) and after the trial phases’ start, the NAOK-HQ initiates contacted via phone: The actual status and the subjective assessment of resilience and exhaustion are evaluated by a standardized questionnaire compared to the information obtained from phase 2 ( $t_0$ ; anamnesis). If the intervention from phase 4 turns out to be inappropriate, the research restarts and a re-entry to phase 3 begins.

## Results

### Evaluation of the first 200 counselings

From June 2019 to March 2024, a total of 200 CAYAs were counseled by the NAOK-PAC. ► **Fig. 2** describes the collective in terms of gender (a), age (b), therapy phase (c), diagnosis (d) and place of residence (e). A small number (3%) made use of the PAC from abroad.

### Recruitment

Two thirds (65%) were recruited via POC, who, informed about the counseling via NAOK flyers. 17% were recruited at events for patients and survivors and 18% found out about the NAOK-PAC independently via internet research.

### CAYAs Characteristics

The percentage of males was 10% higher compared to females (► **Fig. 2a**). The five defined age groups (<6, 6–10, 11–15, 16–

18, > 18 years) were represented with at least 8% ( $N = 15$ ) PAC requests each (► **Fig. 2b**). 66% of the NAOK-PAC (► **Fig. 2c**) took place during follow-up care. 28% were receiving acute therapy or long-term therapy during initial anamnesis. The “other” group includes CAYAs in palliative situations (1%), with other chronic diseases (5%), and with unknown diagnoses (2%). The largest group consists of CAYAs with serious LLE (► **Fig. 2d**). Half of those were affected by a brain or bone tumors. Families whose children had chronic diseases such as familial mediterranean fever, cystic fibrosis and renal insufficiency also requested counseling at greater intervals. Representing 4% of the total collective, the group is allocated to “other”. ► **Fig. 2** shows the distribution of requests by home (federal) state at the time of PAC.

### Feasibility

All persons interested received a PAC including anamnesis and general exercise recommendations. One person died during the 3th phase,  $N = 3$  people suffered a relapse and could not complete phase 4 and 5. No drop-out occurred.

### Aims

Frequently defined targets (multiple answers possible) were “improving health” (88%) and “improving fitness” (75%). “Gaining social contacts”, “finding a sports club”, “optimizing leisure activities” and “participating in camps” were also wished for in the NAOK-PAC (50%).

► **Table 1** Outcome of the first 200 network ActiveOncoKids (NAOK) Physical Activity counselings.

Case-related results	N	%
Basic information	200	100
Connection to cross-clinic NAOK centers	112	56
Connection to a sports club	80	40
Dancing	14	17,5
Badminton, Tabletennis and Soccer e. g.	17	21,2
Martial Arts and Self-defense	15	18,8
Watersports (Rowing, Stand-up-paddling)	16	20
Water-based exercise (diving and rescue swimming)	18	22,5
Connection to specific projects	70	35
(Re)connection to a pediatric oncology centers	30	14
Creation of a training concept by the NAOK	30	14
Connection to NAOK-members and -experts	18	9
Conversations with Physical Education teachers	18	9

## Case-related results

► **Table 1** indicates that all PAC received basic information, with over half of CAYAs connected to a local NAOK center for follow-up PA programme. Almost half of CAYA contacted NAOK-PAC for new sports clubs. Around 20% were interested in dancing, another 20% in sports like badminton, table tennis, and soccer, with a fifth interested in martial arts and self-defense. Ten patients with pronounced LLE such as severe loss of balance, ataxia or severely limited physical resilience expressed the desire to PA in a group with people of the same age. Twelve people affected were connected to inclusive offers. 13 PAC took place in rural regions. Eight of CAYAs were connected to an online service and the adult family members received intensive coaching from the NAOK-HQ so that they could carry out the training independently.

## Case studies

► **Table 2** shows six case studies that varied in specific problem, age, gender, diagnosis, therapy phase, LLE, recruitment, targets, solution strategies and results.

## Discussion

### NAOK advisory approach to facilitate physical activity with a focus on barrier management

NAOK-PAC aims to provide CAYAs with maximum support. Barriers and success depend on various factors such as the family system, local networks and offers, mode of communication, and available time.

### Problem dimensions

The difficulties that impede access to existing sports structures relate to three main factors: a) family and socio-economic structures, and lack of b) a local network and c) suitable sports programme.

a) Family and socio-economic structures include language barriers and severe parental psychological and physical stress and thereof inability to support their children financially or logisti-

cally (transportation, sports wear, registration), despite several support initiatives existing in Germany, such as “No child without sports” and “Education vouchers”. Data on healthy CAYA confirms that children not participating in any physical activity on a regular basis disproportionately come from families with low social status, migration background, or from the new federal German states [21].

- b) Lacking a local network becomes apparent when CAYA are treated in clinics where the NAOK-HQ is not able to offer a specific contact for exercise-related questions. As a result, regional care, sports activities, and personal assessments often fail, and possibly, the results of motor performance tests cannot be obtained either
- c) The lack of suitable sports programme primarily arises in structurally weak and rural regions. These consultations are particularly challenging, as small-town sports infrastructure usually leaves limited choice. There often is a lack of sports facilities such as swimming pools, fitness rooms or gyms as well as qualified professionals [22]. Existing clubs usually offer only a few disciplines or a suitable club can only be reached by traveling long distances. Regardless of where they live, CAYAs with severe disabilities such as ataxia, amputation or physically impaired performance generally have few options.

If several impeding factors accrue, the goals can only be attained through personal commitment of professional staff or loved ones.

### Intervention options

The issues that can make PAC more difficult are offset by three intervention options fostering the NAOK-PAC's success: a) approachable communication, b) a wide network, and c) time available.

- a) Approachable communication focuses on the CAYAs with their needs and requirements, responding empathetically and individually. In the first step, this includes a detailed anamnesis without time limit in a personal (telephone) conversation, using simple language if necessary. The communication structure in NAOK-PAC is resource-oriented, without any pressure, and non-judgemental. The aim is to provide CAYAs with confidence and to encourage them to persevere in achieving their exercise goals with motivation and commitment.
- b) A wide network consists primarily of staff of POC and sports programme. This network plays a key role in providing PAC by conducting relevant assessments, recommending local programme, finding inclusive and target group-specific clubs, informing on camps and sports activities for CAYAs with chronic diseases, and discussing critical case studies across professions (► **Table 2**).
- c) Time is a key factor. NAOK-PAC is an established part of the NAOK-HQ and is incorporated into the work space with a fixed-time quota. This enables to provide advice and connections that can be tailored to temporal needs, allowing creative solutions to be developed with experts, such as the use of online options and intensive searching or even the development of suitable programme.

► **Table 2** Six case studies to exemplify case-specific challenges and approaches to network ActiveOncoKids (NAOK) Physical Activity counseling (PAC).

Case	I	II	III	IV	V	VI
<b>Specific problem</b>	Very anxious family; rural area; lack of sports programme in the Physical Activity counseling	No previous experience in engaging in physical activity; immunosuppression	Rural area; anxious and insecure in behavior; comparison of athletic abilities before and after diagnosis	Participation in physical activities only possible in a wheelchair	Lack of a contact at pediatric oncology centers	Lack of support by the family and social environment
<b>Age / ♀ ♂</b>	4 / ♂	6 / ♀	9 / ♂	12 / ♂	17 / ♂	23 / ♀
<b>Diagnosis</b>	Leukemia	Brain tumor	Wilms' Tumor	Bone tumor	Lymphoma	Brain tumor
<b>Therapy phase</b>	Acute therapy	Acute therapy	Follow-up care	Follow-up care	Long-term therapy	Follow-up care
<b>Recruitment</b>	Internet research by a family member	Printed materials in the clinic	Recommended by befriended family	Assignment via rehabilitation clinic; contact through Physical Education teacher	Recommendation by senior physician of the treating clinic (no NAOK cooperation)	NAOK presence at a young people's seminar
<b>Side-, late- and long-term effects</b>	None	Impaired balance; slight retardation	Reduced physical performance, especially coordination	Amputation and uncertainty in the use of the prosthesis after hemipelvectomy	Fatigue and physical exhaustion	Severe visual impairment; impaired balance; depression and fatigue
<b>Target</b>	Maintenance of physical performance and joy of movement	Improvement of motor skills; joy; ideal promotion of physical activity	Enjoyment of movement despite reduced fitness with peers; Strengthening resilience through sports (as already known as a resource prior to the disease)	Optimal support for participation in Physical Education	Create the physical basis for participation in a five-day mountain tour as part of the final year; recovery of physical disability	Making social contacts; Strengthening of self-esteem; mobility; Improvement of physical performance
<b>solution strategies</b>	<ul style="list-style-type: none"> <li>▪ Contacting the pediatric oncology centers and requesting a prescription for exercise therapy from the attending physician</li> <li>▪ Online training of the physiotherapist in charge</li> <li>▪ Establishing the connection to online programme InterActive (financed by DuMusst-Kämpfer!);</li> <li>▪ Repeated consultations about integrating physical activity into everyday life</li> <li>▪ Provision of motivational movement videos</li> </ul>	<ul style="list-style-type: none"> <li>▪ Establishing a connection to cooperating university and mentoring by a student, who offers an at-home programme once a week</li> <li>▪ Connection to ambulance of pediatric oncology centers</li> <li>▪ Connection to cross-clinic NAOK center incl. climbing classes, skiing trip and weekly sports group</li> </ul>	<ul style="list-style-type: none"> <li>▪ Contact via state sports and city sports federation as well as club with intensive training of the coach with arrangement of a test training</li> <li>▪ Research of experiential education offers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Integration of the NAOK expertise of the teacher and handing-out of leaflet and further literature</li> <li>▪ Integration of the rehabilitation and disabled sports association</li> <li>▪ Attempt to incorporate an integration assistant</li> <li>▪ Request for further training on the topic "wheelchair integration" for teachers with this question in their own federal state at the universities' sports institutes, the teachers' sports association, the state sports association, the disabled sports association, the Ministry of Education and Cultural Affairs, initiatives for people with amputations</li> </ul>	<ul style="list-style-type: none"> <li>▪ NAOK-expertise and contact to Faculty of Sport Science</li> <li>▪ Research for and training of a personal coach</li> <li>▪ Clarification of funding concept by a foundation</li> </ul>	<ul style="list-style-type: none"> <li>▪ Connection to and integration of various events, projects, programme and activities in the context of physical activity</li> <li>▪ Finding a local club</li> <li>▪ Being contactable and answering questions</li> <li>▪ Relaying to NAOK-experts for bike advice and testing</li> </ul>

▶ Table 2 Continued.

Case	I	II	III	IV	V	VI
<b>Results</b>	<ul style="list-style-type: none"> <li>Subjectively assessed improvement in fitness state due to               <ul style="list-style-type: none"> <li>1–2x/week attending exercise programme at hometown physiotherapy practice</li> <li>1x/week Attending online sports programme with NAOK-sports scientist</li> <li>Regular use of the NAOK-YouTube-Channel</li> </ul> </li> <li>Reduction of pressure and anxiety regarding the intensity and frequency of movement during acute therapy through telephone conversations and literature recommendations</li> </ul>	<ul style="list-style-type: none"> <li>Improved fitness level and maintenance/increase of joy of movement               <ul style="list-style-type: none"> <li>Regular participation in movement sessions in a pediatric oncological context including interaction with children who were also formerly ill and their parents</li> <li>Gathering of experiences by moving in outdoor sports areas such as water, snow, and climbing wall</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Strengthening of self-confidence               <ul style="list-style-type: none"> <li>Finding new friends</li> <li>Improvement of fitness level</li> <li>Participation in nationwide flight project with the LSC Leverkusen and flight experience</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Offer by the disabled sports associations to organize a wheelchair basketball day for the class to facilitate understanding among classmates               <ul style="list-style-type: none"> <li>Agreement that the teacher may contact the NAOK headquarters with specific questions regarding the adaptation of the curriculum</li> <li>Participation in a movement camp for children with amputations</li> <li>Feeling of security and self-confidence in the teacher</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Online training of the coach               <ul style="list-style-type: none"> <li>Application for personal training twice a week for 6 months (financed by a donation project and the Elterinitiative) with follow-up registration at the gym</li> <li>Encouragement of the training by writing an exercise plan to improve the basic endurance</li> <li>Strengthening of social ties and self-esteem through successful participation in the hiking trip of his graduating class</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Securing mobility through adapted bicycle               <ul style="list-style-type: none"> <li>Participation and improvement of fitness through weekly rowing at a club; sports-, nutritional, and psychological counseling in the Care for CAYAs-programme</li> <li>Gathering of experiences in moving in outdoor sports areas such as water, snow and climbing wall to strengthen self-effectiveness and exchange with other persons affected</li> </ul> </li> </ul>

## Conclusion

Several studies underline the importance of PA during all phases of a (pediatric) oncological treatment [23, 24]. Looking for programs is often overwhelming for patients and families. Fear of rejection and laborious search for CAYAs-suitable programs often result in paralyzation and despair. Therefore, the process of intention to concrete action in CAYAs is questioned. This shows the relevance of easily accessible and well-networked PAC, taking fears and needs seriously, looking for suitable exercise options in a concept-led way, and supporting families to get into action. Although awareness regarding the relevance of regular engagement in exercise exists in many POC teams and this could also be shown [18], it is currently impossible to provide a complete set of supervised sports and exercise therapy and PAC for all patients during medical treatment or follow-up care and to connect them to suitable PA.

The NAOK-HQ provides a proven PAC concept, in addition to the specific integration of individuals into PA programme. In the long term, it offering supervised sports and exercise therapy and PAC alongside treatment for all individuals is intended.

Currently, 33 POC (55 %) in Germany provide supervised sports and exercise therapy in cooperation with the NAOK-HQ [25]. However, only a few of these have the time resources to provide comprehensive PAC. To our knowledge, no published data exists on PAC concepts for chronically diseased CAYAs. The NAOK-PAC concept introduces an explorative approach, focussing on resource-oriented and individual support from a multidisciplinary network (▶ Fig. 1).

In total, 200 CAYAs have been advised by PAC to date. The NAOK aims at promoting physical, mental and social health through exercise [26, 27] and increasing self-efficacy [28] for CAYAs. The case studies (▶ Table 2) show that advice for CAYAs and adult patients differs [29]. Firstly, hardly any oncology-specific sports groups exist. Secondly, equipment-guided and evidence-based endurance and strength training [30], rarely correspond to CAYAs needs. Thus, it is necessary to (1) jointly provide creative and, if needed, customized solutions and (2) to use existing sports structures. The opportunity to use the NAOK (free of charge) relieves many families. This support requires a well-founded and growing network (▶ Fig. 2) as well as sustainability in the employment of exercise professionals in POC.

## Outlook

The NAOK-PAC programme needs to become even more well-known. Contact and communication modes must be accessible more easily. Moreover, quality standards need to be stated.

To enable communication, an online chat option should be added to the portfolio. Furthermore, detailed documentation and follow-up of cases should be continuous to enable adaptability and optimization. Long-term, the NAOK-PAC model is to be implemented at the local NAOK POC and specifically adapted to each local particularities. However, central networking should be maintained as individual challenging issues often occur more frequently in decentralized settings.

In addition to advanced education courses in “Exercise therapy in paediatric oncology” currently being developed by NAOK members, this concept paper provides a base of knowledge basis and raises awareness of the relevance of PAC.



Cooperation and exchange with advisory structures in the context of other chronic diseases, such as Mukoviszidose e.V. (<https://www.muko.info/was-wir-tun/beratung-und-unterstuetzung/sportberatung>, retrieved on XX.XX.2024), is recommended, taking into account similarity of challenges and limitations in all pediatric patients. Even if the specific health benefits cannot yet be confirmed here, the benefits in terms of participation in sport are obvious. NAOK PAC is an innovative concept that enables nationwide access to physical activity structures.

## Contributor's Statement

Contribution to study concept and design: G. Gauß, S. Kesting, J. Boos, M. Götte Data collection: G. Gauss, D. Reinhard, M. Götte Data analysis and interpretation: G. Gauss, S. Kesting, J. Boos, M. Götte Drafting the manuscript: G. Gauss, S. Kesting, J. Boos, M. Götte Revising the manuscript: G. Gauß, S. Kesting, J. Boos, D. Reinhard, M. Götte Letter to the editor: G. Gauß.

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## Conflict of Interest

The authors declare that they have no conflict of interest.

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