

Good Practice on Co-Creation

Name/title of activity

Parent2Parent Support – Peer Mentoring Programme for Parents of Children and Adolescents with Cancer

Name and Country of the entity leading/coordinating the activity

NGO / KARKINAKI Awareness For Childhood and Adolescent Cancer / Greece / www.karkinaki.gr

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Context

Parent2Parent Support emerged from the growing need to address the psychosocial challenges faced by families navigating childhood and adolescent cancer in Greece.

Evidence from paediatric oncology literature consistently shows that parents / primary caregivers gain significant benefits from connecting with other families who have experienced cancer. Knowledge exchange, emotional support, and a shared understanding of the journey are among the most valued outcomes. Both mothers and fathers report that engaging with peers who “have been through it” enables them to speak more openly than they often can with health professionals. These peer exchanges not only build confidence in managing the cancer journey but also help families navigate critical post-treatment transitions, including reintegration into school and work, re-establishing family dynamics, and adapting to the “new post-treatment normal.”

Recognising the absence of formal peer support structures for parents in Greece, KARKINAKI, an NGO that focuses on advocacy, awareness and psychosocial support for families affected by childhood and adolescent cancer, initiated a co-creation process in early 2023.

Parent2Parent Support was co-designed and co-implemented by parents of children with cancer, working alongside mental health and healthcare professionals. A central aim of the programme was to position parents as equal partners, using their lived experience and expertise to “give back” to others caring for childhood cancer patients and survivors. The goal was to create a sustainable model of informal psychosocial support rooted in lived experience - one that offers both practical and emotional assistance to parents, while amplifying their voices in shaping the future of psychosocial care services.

Overview of the activity

1. Ideation

The concept for the Parent2Parent Support programme stemmed from shared experiences and repeated feedback gathered from primary caregivers who attended KARKINAKI's psychoeducational webinars. In these sessions, **parents** had an opportunity to share their stories alongside the educational content delivered by healthcare professionals. However, they **repeatedly highlighted that perhaps the most valuable takeaway was the opportunity to connect with other families facing similar challenges.**

Recognising this unmet need, the programme's coordinator, herself a mother of a childhood cancer survivor, conducted preliminary research to explore whether similar initiatives existed in Greece. Finding no structured models in place, KARKINAKI initiated a consultation with a small group of parents and mental health professionals to map the community's needs and outline an initial vision.

2. Design/development

Seven parent volunteers participated as equal partners in a series of monthly workshops over a nine-month period, co-facilitated by the programme's coordinator and supervised by the organisation's scientific advisory team, which included a social worker, a psychologist, and a paediatric oncologist.

Together, they reviewed existing peer-reviewed literature on peer-to-peer support programmes and **co-developed every aspect of Parent2Parent Support:** the programme's structure and core values, eligibility criteria for both peer mentors and participants, peer mentor training content, key responsibilities for all parties, and ethics and safety protocols.

The group also co-created its own "Working Together Framework", grounded in the key principles of co-creation:

- Sharing power
- Including all perspectives and skills
- Respecting and valuing everyone's knowledge
- Reciprocity and mutuality
- Building and maintaining relationships
- Joint understanding and shared learning

3. Implementation

Of the seven parents who participated in the co-creation of the Parent2Parent Support programme, six chose to be trained as Peer Mentors. The programme coordinator also reached out to other parent members of KARKINAKI who met the inclusion criteria for Peer Mentors, inviting them to join the training. While two parents expressed interest, they were unable to commit to both the training sessions and the year-long commitment. Ultimately, six parents completed the training and began their volunteer roles as Peer Mentors.

Over the course of one year, these Peer Mentors were individually matched with ten parents seeking peer support. Most peer-to-peer support relationships ran for a period of approximately five months, with regular meetings - typically held on a bi-weekly basis -

conducted either online or via phone, as the majority of parents seeking support lived outside Athens and other urban centres.

To ensure quality, consistency, and the wellbeing of both mentors and participants, all Peer Mentors committed to attending monthly group supervision sessions led by a mental health professional. **These sessions provided a safe space for reflection, peer learning, and the exchange of strategies, as well as ongoing feedback and development of common counselling skills for mentors.**

4. Evaluation

The evaluation of the Parent2Parent Support programme drew on both quantitative and qualitative data, collected through **questionnaires and interviews with participating parents volunteers, Peer Mentors, and parents who received peer-to-peer support. All materials were co-created with the 7 parent volunteers and KARKINAKI's scientific advisory team.**

All parents who provided feedback reported feeling comfortable sharing their experiences and concerns with their Peer Mentor and **expressed high satisfaction** with their mentor's ability to listen actively and respond with empathy. They **described the overall experience as very positive**, highlighting that the presence of a mentor who listened without judgment and without pressure was in itself transformative.

Peer Mentors also reported significant personal benefits. They described feeling more resilient and empowered, with five out of six stating that the training and ongoing supervision enhanced their ability to build trust and support other parents. All identified active listening and empathy as key interpersonal skills they had strengthened. One in three said the experience inspired them to pursue further training or even a career shift into mental health-related professions. Importantly, every Peer Mentor expressed their wish to continue in the role, describing the experience as a way to reclaim meaning from a difficult chapter in their lives.

Good Practice Indicators¹

1. Where all relevant stakeholders involved in the co-creation process?

Did you succeed in involving all relevant stakeholders? Which stakeholders were involved in the co-creation process and in what ways?

Fully implemented

The concept for the Parent2Parent Support programme was based in shared experiences and repeated feedback from parents, so arguably, they were engaged from the very inception of the idea. The programme coordinator, herself a parent of a childhood cancer survivor, brought her lived experience into every stage of the process.

During the development phase, parents at different stages of the cancer journey (both those with recent experience and those further along) took the lead in shaping the programme. They participated as co-designers and co-facilitators in a series of workshops, supported by

¹ According to Mental Health Europe's Co-creation approach

a multidisciplinary scientific advisory team. Ahead of its launch, the programme was also reviewed by external stakeholders, the healthcare staff of a major paediatric oncology hospital in Athens, including the Head of paediatric nursing, a paediatric oncologist, and a paediatric oncology nurse. Ideally, we would have engaged external clinical partners earlier in the process; however, building this alliance required time, as peer-to-peer models and co-creation methodologies are not well established in the paediatric oncology landscape. As a result, the scientific advisory team acted as the primary source of clinical and psychosocial expertise in the early stages of the programme development.

Parent volunteers reviewed existing peer-reviewed literature on peer-to-peer support programmes and co-developed all aspects of Parent2Parent Support: its structure and core values, eligibility criteria for both peer mentors and participants, peer mentor training content, roles and responsibilities, and safety protocols. In this way, all relevant stakeholders—parents, healthcare professionals, and patients (through KARKINAKI)—were fully engaged in the co-creation process from start to finish.

2. Did participants represent diverse profiles within their stakeholder group?

For example, consider the diverse experiences and expertise of individuals facing mental health problems, as well as those of their families, supporters, service providers, and community members, and take into account factors such as age, gender, socio-economic background, religion, and more. If yes, how did you ensure diversity and inclusiveness? If not, what were the reasons?

Partially implemented

While we made conscious efforts to include diverse voices in terms of gender, geography, and stage of treatment, achieving broader representation remains a goal for future iterations of the programme.

A strength we are especially proud of is the inclusion of a bereaved parent in both the co-creation process and as one of the six trained Peer Mentors. Parents who have lost a child to childhood or adolescent cancer often experience profound isolation and a higher risk of mental health challenges. Incorporating their perspective into the programme not only enriched its design but also hopefully created a valuable source of additional support for this group.

Another important achievement was the participation of two fathers, both in the co-creation team and as Peer Mentors. Research shows that fathers are generally less likely to seek mental health support but are more inclined to connect with other men who share similar experiences. Hence our two Peer Mentors serve a dual role: they offer peer support to other fathers, while also modelling the benefits of having sought professional psychological help to male caregivers.

Looking ahead, our aim is to further extend representation by including parent voices from across Greece. Many parents seeking peer support live in remote or rural areas, where access to services is limited, and the experience of the cancer journey and survivorship can be very different from that of families in urban centres. We recognise that these perspectives are essential to fully shaping and evolving the programme.

3. Were all resources needed for everyone's full engagement secured and allocated in a transparent way?

If yes, what types of supports were provided, and how were these resources managed? If not, what were the reasons?

Fully implemented

Human resources The co-creation process was led by the programme coordinator, herself a mother of a childhood cancer survivor and experienced researcher, supported by KARKINAKI's scientific advisory team (psychologist, social worker, paediatric oncologist). The core group consisted of seven parent volunteers, representing different cancer types, ages at diagnosis (from toddlers to teenagers), and post-treatment stages. They co-designed the peer mentor training and, as most went on to become Peer Mentors, contributed directly to refining and adjusting the programme during implementation.

Time The co-creation phase spanned nine months, with monthly workshops co-facilitated by the programme coordinator. Sessions involved literature review, open discussion, collaborative decision-making, brainstorming, and scenario exploration. Parents committed to sustained engagement, recognising the need for time to build trust, develop ideas, and reach consensus. Meeting times were set in consultation with parents to accommodate family and work schedules. Similar principles were followed in scheduling participation of healthcare and mental health staff, as well as KARKINAKI's scientific advisory team. Since the coordinator of the programme had some prior experience with patient involvement projects, some potential obstacles were anticipated from the outset, with adjustments made at various time points.

Working with people with lived experience requires flexibility — not only in terms of availability, but also in recognising the emotional weight that can come with revisiting treatment-related experiences. To support this, information and resources were shared well in advance, giving parents time to review and process materials at their own pace.

Scheduling was another area where prior experience proved valuable. The differing availability of the scientific advisory group and parents was anticipated, and responsibilities were distributed among parents, with workshop time used to share feedback and consolidate learning. This approach ensured progress was made, even when not all stakeholders could be present at the same time.

Recognising the time-intensive nature of co-creation, extra time was built into the original plan to accommodate potential delays and avoid placing pressure on co-creators. This was particularly important at decision-making milestones and when new skills — such as reviewing academic literature or interviewing healthcare professionals — were introduced. Although, as expected, some delays occurred despite best efforts, these did not compromise the quality of collaboration.

Finances The programme was delivered within KARKINAKI's operational budget, supplemented by some fundraising. Costs covered included training materials, supervision for Peer Mentors, and coordinator fees. Travel expenses and catering for in-person sessions were also covered, ensuring participation came at no financial cost to parent volunteers (at the co-design stage) or Peer Mentors (during implementation).

There are currently no statutory compensation rights for voluntary work in Greece. Under Greek law, volunteers cannot receive wages without being formally classified as employees, which would require legal employment status and associated obligations. For this reason, compensating parent volunteers financially was not possible within the scope of the project.

Given these constraints, KARKINAKI ensured that participation in the co-creation process did not create financial burden for parents. While parent volunteers were not paid, the organisation covered travel expenses, catering, and materials during in-person meetings. Same principles applied for Peer Mentors.

Diverse needs Materials were prepared in clear, accessible Greek, with foreign literature translated where needed. Guidance on online platforms and research processes was offered to ensure full participation. Parent volunteers actively worked to involve everyone, even co-leading interviews with healthcare and mental health professionals—demonstrating the confidence gained through their involvement. The inclusion of a bereaved parent and two fathers reflected the programme’s commitment to diverse representation, while expanding socio-economic and regional diversity remains a priority for future iterations.

4. Were participants aware of the expertise each was bringing?

If yes, how did the stakeholders' knowledge and skills contribute to the activity, and how was this expertise leveraged to support the co-creation process? If not, what were the reasons?

Fully implemented

There was a conscious effort from the outset to highlight and value each member’s contribution. **Particular emphasis was placed on helping volunteer parents recognise the unique expertise that comes from lived experience.** The programme coordinator set the tone by openly sharing both her personal journey and her professional skills in research design, facilitation, and project management.

Parent volunteers represented different cancer types, ages at diagnosis, treatment phases, and post-treatment stages (including bereavement). **This diversity allowed the group to learn from one another and to incorporate varied perspectives:** from managing treatment side effects to navigating reintegration into school and work, to coping with long-term side effects and grief. Fathers were praised for their openness and input as it modelled the importance of male engagement in emotional support and peer connection.

Healthcare and mental health professionals contributed clinical expertise, safeguarding guidance, and an understanding of established frameworks in paediatric oncology. They ensured that the Parent2Parent Support programme design was safe, ethically sound, and aligned with best practice, while also gaining better appreciation for the perspectives and expertise derived from lived experience.

Our intention, throughout was to demonstrate how professional knowledge and lived experience can work in partnership — fostering a culture of respect, trust, and shared ownership.

5. Did participants understand what co-creation is and how it works?

If yes, what measures were taken to ensure all participants had a clear understanding of co-creation and its process? If not, what were the reasons?

Fully implemented

Volunteer parents were supported from the outset to understand what co-creation is and how it works, both in general and in the specific context of paediatric and adolescent cancer. They received a one-page overview outlining the concept of peer-to-peer support, the meaning of co-creation, its key benefits, and potential outcomes for the community. **The first workshop was dedicated entirely to explaining the main principles of co-creation and exploring what these would mean in practice for everyone involved.**

Early in the process, the group co-developed a “*Working Together Framework*”, which became the foundation for collaboration. Creating this framework together allowed participants to put theory into practice and see first-hand how this approach would shape the Parent2Parent Support programme.

6. Was the focus and expected outcome of the piece of work/activity to be done in co-creation been jointly discussed and agreed upon?

If yes, what methodology was used to define the scope and expected outcomes? If not, what were the reasons?

Mostly implemented

The original idea for the Parent2Parent Support programme stemmed from shared experiences and repeated feedback gathered during KARKINAKI’s psychoeducational webinars for primary caregivers. Recognising this unmet need, the programme’s coordinator conducted preliminary research to explore whether similar initiatives existed in Greece. Finding no structured models in place, KARKINAKI initiated a consultation process with a small group of parents and mental health professionals to map the community’s needs and outline an initial vision.

7. Was a group agreement in place?

If yes, what was the process for establishing the modalities of collaboration, communication, and decision-making? If not, what were the reasons?

Fully implemented

During the second workshop, parent volunteers were invited to work together to create their own “*Working Together Framework*.” This group agreement captured the values and vision that would guide the team’s collaboration, including respectful engagement, positive communication strategies, clear boundaries, and mutual commitment. It ensured that all voices were heard, responsibilities were clearly defined, and the environment remained safe and constructive throughout the co-creation process. Sharing the framework with other stakeholders helped set the tone for broader collaboration with healthcare professionals.

The framework was built on the following principles:

- Sharing power
- Including all perspectives and skills
- Respecting and valuing everyone’s knowledge
- Reciprocity and mutuality
- Building and maintaining relationships
- Joint understanding and shared learning.

8. Was there an action plan that outlined the steps involved in your co-created activity?

If yes, could you please elaborate on the process of formulating your action plan? If not, what were the reasons?

Fully implemented

An initial action plan was drafted by the programme coordinator ahead of the first workshop, drawing on literature and resources from similar peer support and co-creation projects. This served as a starting point and was presented to the co-creators (parent volunteers) during the first workshop. **At the end of each workshop, we revisited the proposed timelines, responsibilities, training needs, and evaluation checkpoints, making collective adjustments where required. While flexibility was encouraged, certain deadlines and deliverables had to remain fixed** to accommodate the involvement of other stakeholders - such as healthcare teams - ensuring the launch date was met. However, having a full overview enabled co-creators to feel genuine ownership of the project, and to remain invested and responsive to the agreed schedule.

9. Were practical aspects, such as scheduling and accessibility, considered to accommodate everyone's circumstances and ensure their full participation?

If yes, in what manner were practical aspects considered to accommodate everyone's circumstances? If not, what were the reasons?

Fully implemented

We took deliberate steps to ensure that all parent volunteers could participate fully and comfortably in the co-creation process. **Scheduling was approached collaboratively**, with proposed meeting times discussed in advance to accommodate family, work, and caregiving commitments. Workshops were arranged in the late afternoon to suit the group's availability.

Accessibility was also a key consideration. All materials related to the design, implementation, and evaluation of the Parent2Parent Support programme were stored in a shared folder, translated where necessary, and prepared in clear, accessible Greek. Digital literacy was assessed early on to ensure that all parent volunteers and other stakeholders could contribute with confidence. We also made a conscious effort to address different learning styles by incorporating a variety of approaches, including visual aids, reading materials, role-play exercises, creative activities, and mind mapping

While the group requested workshops to be in-person, where possible, online participation was an option. Finally, to remove financial barriers, **the organisation covered travel and catering costs** for in-person workshops.

10. Were all actors who were involved in co-creation able to contribute their perspective to the evaluation?

If yes, how did their insights enrich the evaluation process? If not, what were the reasons?

Fully implemented

The evaluation of the Parent2Parent Support programme was co-created with parent volunteers, Peer Mentors, the programme coordinator, and KARKINAKI's scientific advisory team. A mixed-methods approach was adopted, with a strong emphasis on qualitative feedback to capture the personal impact of the programme's co-design, implementation, and co-evaluation.

Data was collected at multiple points and through various methods, including:

- Post-workshop feedback from parent volunteer (co-design phase)
- Reflective journal entries by the programme coordinator (co-design / implementation phase)
- Semi-structured interviews with members of KARKINAKI's scientific advisory team (co-design, implementation phase)
- Monthly group supervision reflections from Peer Mentors (implementation phase).

The parent volunteers - the main actors in the evaluation design - played a central role in shaping the material used. They provided ongoing feedback throughout the co-design phase and were actively involved in creating and conducting the semi-structured interviews with the scientific advisory team. This core co-creation group also developed questionnaires and interview guides for the overall Parent2Parent Support programme. These tools were used with both Peer Mentors and parents who received peer support, allowing us to measure the success of the programme against the key aims we set out to achieve.

11. Did you apply co-creation to evaluate a) your activity and b) the effectiveness and impact of the co-creation approach both in the short and long term?

If yes, what kind of process and tools did you use? If not, what were the reasons?

Partially implemented

We applied co-creation to evaluate the activity itself—the Parent2Parent Support programme—by involving parent volunteers, Peer Mentors, the programme coordinator, and KARKINAKI's scientific advisory team at various stages of the evaluation process. The evaluation design was co-created with the core parent volunteer group, who shaped the tools, defined the priorities, and ensured that both qualitative and quantitative data captured the outcomes most meaningful to those with lived experience and aligned with the programme's key aims.

Our focus was on assessing whether the programme met its stated objectives, how it was experienced by participating parents and Peer Mentors, and what impact it had on their isolation, resilience, and sense of community. While a structured evaluation of the co-creation approach, both in the short and long term, would have been valuable in highlighting the effectiveness of this methodology in developing services for vulnerable groups, time and budget constraints made this impossible. The insights gathered, however, provide a strong foundation for expanding our evaluation scope in future iterations.

Lessons Learned

What were the lessons learned from your co-creation process?

Please describe the main challenges encountered during the co-creation process and how you addressed them. Also, outline the factors that supported the co-creation process. Feel free to provide examples if relevant.

The co-creation of the Parent2Parent Support programme reinforced the value of designing services alongside people with lived experience. Working with multiple stakeholders also confirmed what is widely recognised in the field: **co-creation requires time, resources, structure, and flexibility**. Perhaps the most meaningful achievement was the empowerment, personal growth, and even professional development of the seven **parent volunteers**. Their **transformation into equal partners** in designing the programme not only shaped the programme, but **also helped shift how other stakeholders perceived lived experience in paediatric oncology**, recognising, perhaps for the first time that experts by experience can improve services and align them with the needs of the community.

A key lesson was the importance of building trust from the outset. Parent volunteers brought personal experiences, and revisiting treatment and survivorship journeys at times triggered emotions of loss, and vulnerability. To support this, we established a clear “*Working Together Framework*” from the start, paced the work, and created space for reflection and emotional expression during workshops. For Peer Mentors, monthly supervision and ongoing training further ensures emotional safety, allowing them to participate confidently and meaningfully.

A practical challenge emerged around logistics and resource constraints. Parent volunteers balanced caregiving and professional responsibilities, while healthcare partners had limited time available. Anticipating this, as is common in the field, flexibility was built into timelines from the beginning. Tasks were divided, meetings held in hybrid formats where possible, and information was provided in advance and in accessible language. As a small non-profit, removing financial barriers was key, so funds were secured to cover travel and catering costs for parents participating in in-person workshops.

Finally, the process highlighted the importance of representation and ongoing inclusion. While we successfully involved mothers, fathers, and a bereaved parent, expanding socio-economic and regional diversity remains a clear priority. Families living beyond urban centres often face greater psychosocial needs, with fewer local support available to them. Their participation as beneficiaries reaffirmed the necessity of continuing to reach and engage these families, ensuring their perspectives and needs are fully reflected in future iterations of the Parent2Parent Support Programme.