Patient public engagement and involvement in palliative care research: Co- designing best practices with children and young people in a low- and middle- income settings

Eve Namisango
Eve.namisango@africanpalliativecare.org
African Palliative Care Association
Lorna K Fraser
King's College London
Kennedy Nkhoma
King's College London
Julia Downing
International Children's Palliative Care Network
Catherine Evans
King's College London
Elizabeth Nabirye
Palliative care Education and Research Consortium
Elizabeth Namukwaya
Makerere University
Emmanuel Luyirika
African Palliative Care Association
Elly T Katabira
Makerere University
Jane Nakaweesi
Baylor College of Medicine Children’s Foundation
Yvonne Karamagi
Mildmay Uganda
Juliana Kayaga
Makerere University
Annet Nakirulu
Mulago National Specialised Referral and Teaching hospital
Dianah Hossana
African Palliative Care Association

Moses Muwanga
Ministry of Health
Richard Harding
King's College London

Research Article

Keywords: Palliative Care, child engagement, resource-limited settings, child-centred practices, research involvement, co-design

Posted Date: May 11th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-9486840/v1

Additional Declarations: No competing interests reported.

Abstract

Background: Engaging children in research processes is recognised as best practice, as it ensures studies are relevant and responsive to their needs. Limited evidence exists on effective approaches for engaging children with serious illnesses, particularly in palliative care and in resource-limited settings.

This study aimed to work with children and young people with serious physical illness to co-design processes and practices for meaningful engagement and involvement in palliative care research within resource-limited settings.

Methods: A co-design workshop approach was used to develop best practices for engaging and involving children in research. Twenty participants living with serious illnesses were purposively recruited from three heterogeneous tertiary care services in Uganda. Guided by the NIHR framework of public engagement and involvement, workshops were facilitated by members of a multi-disciplinary team, parents, and caregivers. The resulting practices were piloted in our research with the advisory involvement of the young people.

Results: The process established 9 principles for engaging and involving children in palliative care research were co-designed. Examples include: Involve children early to ensure that objectives, questions and outputs are relevant to their needs and concerns; Creative and flexible co-design of workshop and meeting agendas makes sessions enjoyable, thus increasing attendance; Involvement of children in the design of research study materials ensures that they are child-centred and easily understood; Sharing decision-making power with children to strengthen efficiency, coordination, communication, and group management.

Conclusions: This study presents approaches to engaging children in research and highlights some of the benefits of doing so. Working collaboratively, strategies were co-designed for engaging and involving children with serious illnesses across the research life cycle. The process produces child-centred research practices, outputs, and dissemination strategies, and provides practical models for workshop agendas and guidance on managing child advisory groups. These findings can inform future research, practice, and policy to ensure children are meaningfully represented in palliative care research and promote more inclusive and responsive research practices.

Plain English summary

It is widely recognized as a best practice to involve children in research to ensure that studies directly address their actual needs. However, there is very little guidance on how to effectively engage children facing serious illnesses, particularly within palliative care and in settings with limited resources.

To bridge this gap, a study in Uganda worked directly with 20 young people living with serious physical illnesses. Through a series of interactive "co-design" workshops, a multidisciplinary research team,

alongside parents and caregivers, collaborated with these young patients to figure out the best ways to include them in health research.

We established nine key principles for involving young people in palliative care studies. Important takeaways include the need to bring children into the process early so the research goals are relevant to their personal concerns, and the use of creative, flexible meeting agendas to make the experience enjoyable and boost attendance. Furthermore, having children help design study materials ensures that the information is actually easy for other young people to understand. The study also found that sharing decision-making power with children greatly improves communication, efficiency, and group coordination.

Ultimately, this project highlights the profound benefits of working collaboratively with young patients across the entire research life cycle. By applying these newly co-designed strategies and practical workshop models, future researchers, healthcare practitioners, and policymakers can ensure that studies are truly child-centered, inclusive, and responsive to the real needs of children

Introduction

Globally, it is estimated that over 21 million children live with serious health conditions that could benefit from palliative care, and the majority of these (98%) live in low-and-middle income countries [1]. Palliative care improves patient and family outcomes of care and alleviates suffering associated with serious illnesses [2]. The World Health Organisation (WHO) recommends palliative care as an essential health service under Universal Health Coverage, emphasising the need for person-centred care [3]. However, access to palliative care is severely limited[4]. Person-centred care focuses on individuals, families, and communities as key stakeholders in health systems, who should be involved and engaged [5]. Patient and Public Involvement and Engagement (PPIE) involves active patient participation in research which informs the care that they receive by taking into consideration their experiences [6]. To stimulate the development of person-centred care for children and young people, there is a need to engage and involve them in research, as this shapes the care they receive. Currently, the majority of primary evidence for person-centred care models and their outcomes derives from adults in high-income countries[7, 8]. Children and young people with lived experience can make valuable input into the design and the delivery of health services [9]. The engagement and involvement of patients has been associated with reduced admissions, and improved efficiency [10]. It is now a recommended strategy for improving the quality of health services [11], and is in line with the Almaty Declaration for Primary Health Care [12].

Although there is a consensus that there are benefits for engaging and involving patients in research, a dearth of evidence exists on how best to achieve this in practice [13]. The lack of evidence is a major concern in low- and middle-income countries where the need for research is greatest. In a study that established a Young People's Advisory Group in palliative care in Europe, the authors concluded that it was feasible to equip children with research skills using activities that they enjoyed [14]. A scoping review of PPIE with young people who have chronic conditions reported studies with involvement in design, recruitment, data collection, analysis, and dissemination [15]. Cooks et al (2019) identified various approaches to engaging patients in research including collaboration and research planning [16]. However, most existing studies originate from high-income countries and often do not specify strategies used [15]. Evidence on PPIE strategies, associated activities, and impact will move the field move to optimally meaningful engagement [16].

This study aimed to work with children and young people with serious physical illness to co-design processes and practices for meaningful engagement and involvement in palliative care research within resource-limited settings.

Methods

We used a co-design workshop approach to develop and pilot the processes and practices for engaging and involving young people living with serious illnesses in paediatric palliative care research. Our approach was underpinned by the National Institute for Health Research (NIHR) framework for patient and public engagement and involvement (Table 1).

Table 1
The NIHR principles for patient and public engagement and involvement

Principles
1-Patient and public engagement and involvement should be appropriate and relevant to the local context and research aims
2-Inclusive opportunities -Involve the community at the earliest opportunity and throughout the process
3- Understand your communities
4- Build and open and trusting relationship
5- Facilitate power-sharing
6- Be flexible and creative
7- Embed monitoring, evaluation, and learning

Identifying the young people to work with

We purposively recruited young people (10–19 years) living with serious illnesses such as cancer, heart failure, HIV, blood disorders, and sickle cell disease currently receiving palliative care from tertiary care facilities in Uganda. We opted for this age group because evidence shows that from the age of 10 years young people can engage in discussions comfortably engage in group discussions, while in-depth interviews work better for the middle age[17].

Inclusion criteria were: a confirmed diagnosis of a life limiting or life-threatening condition; awareness of their diagnosis; aged between 10 and 19 years; willingness to provide assent; availability of parent or guardian to provide informed consent; and the ability to read and write. Young people who did not meet these criteria or who were too unwell to participate in the study (as determined by their treating clinical team)procedures were excluded.

Young people were recruited from three tertiary care services: a large tertiary care centre for children living with HIV/AIDS, the National Referral Teaching Hospital Uganda's for children with cancer, sickle cell, and neurological conditions, and a paediatric palliative care specialist facility. The latter cares for children with cancers who are receiving care from the Uganda Cancer Institute. In such instances the facility offers psychosocial and spiritual care, and the cancer institute offers the physical care including pain and symptom control. The home care service also provides care to children living with HIV/AIDS.

Recruitment

Working with young people at the HIV service, we co-developed an information flyer describing the engagement activity, inviting them to participate in discussions and a workshop aimed at developing best practices for involving young people in paediatric palliative care research. The young people were approached by their social workers, who provided information about this activity. Those who expressed interest were provided with consent forms (for participants aged 18 years), then assent and guardian consent forms for the minors (for those aged 10–17 years). All materials were provided in their preferred language (English, Luganda or Runyakitara). Participants were given one week to review the information and notify counsellors or social workers of their interest in participating in the two-day workshop, (see Fig. 1 for further details).

Ethical approval

to conduct the study was obtained from Kings College London, the Mildmay Uganda Research and Ethics Committee (Ref: 0107–2023), and the Uganda National Council for Science and Technology (Ref: HS3578ES). All study participants provided written informed consent or assent prior to participation.

Co-design procedures

The first workshop was a two-day focus group workshop held on 14th to 15th December 2023 at a Hospital Guest House in Kampala, Uganda. This workshop specifically aimed to gather the perspectives of children and young people living with serious illness and their caregivers into the research process. Participants attended the workshop, including children and young people, caregivers, and members of the research and clinical teams. Participants were drawn from the 3 clinical sites-Mulago Hospital, Mildmay Uganda, Kawempe Home Care and we also had the Ministry of Health representatives. The workshop was facilitated by the team from APCA who guided discussions and ensured that activities were accessible and engaging for children and young people. Facilitators encouraged open participation and supported children and young people to express their views in a comfortable environment.

The workshop was conducted over two days, with sessions typically running between 9:00 am and 4:00 pm, including breaks for refreshments, play and lunch.

The sessions were designed to be participatory and child friendly (included role play, play, use of games, and videos for learning. Activities included small-group discussions, brainstorming exercises and interactive discussions intended to encourage children to share their perspectives on engaging children in research. The key recommendations were summarised in slides and presented by three representatives from the children and young people's group. These were adopted for use in the parent study, which needed these best practices to inform their children and young people engagement strategy.

The second workshop were held for two days on 22nd and 23rd February 2024, at Makindye Country Club in Uganda and each day ran from approximately 8:00 am to 4:00 pm, with scheduled breaks for tea, play and lunch. The aim of the workshop was to review resources for children's palliative care leveraging on recommended practices for engaging children and young people in research. The workshop involved presentations on overview of the resources, followed by discussions small and bigger groups which focused on children and young people giving feedback on what could be improved. The feedback was documented by a note taker (LF). At this workshop the useful practices gathered across the three workshops was put together in a document and were reviewed by the members of the team, attending children and young people and their caregivers.

Results

Participants

A total of 20 young people participated in the workshop, of these 10 (50%) were female. The age range was 10–19 years (see Table 2 for details).

Table 2
Socio-demographic characteristics of the young people (n = 20)

Variable	**N**
Study site	
Mildmay Uganda	8
Mulago National Referral and Teaching Hospital	8
Kawempe Home Care	4
Gender	
Male	10
Female	10
Age group	
10–13 years	10
14–19 years	10
Diagnosis	
Cancer	6
HIV	8
Sickle cell and other blood disorders	6

Facilitators

The workshop moderators included social workers (4), nurses (2), play therapist (1), paediatricians (2), adolescent counsellor (1), parents/guardians (2), clinical officer (1), child life support person (1).

Main findings

The co-design workshop established nine principles.

-Principle 1: Community Engagement and Involvement (CEI) practices should be appropriate and relevant to the local context and research aims

The proposed main roles for young people included participating in the assenting/consenting, recruitment, and dissemination of findings. These activities would foster friendship and a sense of belonging among the children and young people. For example, young people with lived experience can articulate details of the study and communicate how certain procedures can affect them and describe strategies for managing any potential distress associated with a procedure. All members were confident they could support the dissemination of study findings using social media fora commonly used by their peers.

The young people noted that they should participate in the interpretation or validation of study results. For example, if a study aims to determine the priorities of children and young people living with a serious illness, they can review a list of themes and then provide feedback on how accurately these reflect their real-life concerns as patients and that of their families.

"Sometimes findings may not mirror what is important to us, we should be asked if the results are aligned to what we said. Sometimes misinterpretations may occur, also some things can be minimised, yet they matter to us". Respondent 03

Participants also noted the young people would make an important contribution in reviewing data collection tools and consent forms, to confirm appropriateness of language. They argued that they use a unique language which includes short sentences and simple words and many adults miss out on this.

"We can support the peer reviewing of the data collection tools and the assent/consent forms, we know our language. Sometimes documents are written in complicated language which does not work for us, the young people." Respondent 05–11 years

We also identified the important role of young people in reviewing consent forms to confirm appropriateness of language and guiding their fellow young people through the consenting process. Additionally, their participation in research priority setting helps ensure that studies address their actual needs and that best practices are shared with those who need to know about them, leading to positive action on their concerns.

-Principle 2: Involve the community at the earliest opportunity and throughout the process

Participants identified the need for young people to support and guide the study team at the start of study, and they supported and guided the team through the entire research process. Their ongoing engagement allowed them to advise the study team at all the various stages of the research process, ensuring the research was relevant to their perspectives.

-Principle 3: Understand your communities

We began with an open discussion about the nature of research to build rapport between the workshop convenors and the young people. This approach helped us learn more about the community and enabled us to work collaboratively to co-design effective methods for communication and dissemination of research findings.

-Principle 4: Build and open and trusting relationships

The young people proposed several strategies to keep the group connected, and through WhatsApp groups, a regular schedule of meetings or phone calls were arranged via their guardians. It was also recommended that they receive reimbursement for transport costs and a token of appreciation for every meeting attended. The involvement of guardians was emphasised, as some young people required an escort to meetings during the review of assent forms. Guardians also monitored the young people's safety on the road while traveling to and from meeting venues. Adopting these principles strengthened our working relationship with the young people, and they freely shared their views and contributed valuable input as needed.

"*We can have phone calls, or physical visits here for updates or we can use WhatsApp groups. I would say it is important to engage our guardians so that they are aware. They just need to know the dates and the venue for these events*." Participant 07–15 years

"*But some of us have to be escorted along, it is important to have our guardians engaged and involved, they can help us in making some decisions*." Participant 03–10 years

-Principle 5: Facilitate power-sharing

To facilitate power sharing in terms of governance, the group members democratically elected three office bearers: a chairperson, vice chairperson and secretary. Before this election, workshop facilitators briefed group members on the roles and qualities required for each leadership portfolio. Power sharing made group management and decision- making more efficient. The elected leaders were able to engage their peers on issues of communication, mobilisation, and decision-making, and then relay feedback to the study team.

-Principle 6: Be flexible and creative

For flexibility and creativity, we co-designed processes for engagement with children and young people in palliative care research, and this made all our activities child-centred, inclusive and acceptable. The participants decided that a typical PPIE agenda for young people should include play interludes, music, dance and drama, good meals, and refreshments, and shared learning. The preferred approaches to include studying in groups, role play, use of films, visuals, and illustrations. Below is a typical agenda proposed by the young people (see Fig. 1).

-Principle 7: Provide children and young people with learning opportunities

To empower the young people to support research in different capacities, interpersonal skills, self-confidence, social media engagements, communication and presentation skills, the participants identified a need for training in the following areas (see Table 3).

Table 3
Training needs identified by the young people

Training need	n
Interpersonal skills and self confidence	20
Professional social media engagement – how to use WhatsApp, Twitter space	20
Communication and presentation skills	18
Compassionate support	17
Research skills	15
The consent process	15
*Multiple response where is asterisk in the table?	

-Principle 8 Child friendly dissemination of research findings mechanisms

The children proposed child several child-centred approaches for sharing study findings. These included using social media channels such as TikTok, Twitter (X) and YouTube, as most young people access information and seek guidance through these platforms. Other avenues proposed included summarising key findings in short booklets, and using music, art, and drama to communicate key messages from the research. An additional option proposed was physical meetings or workshops. Traditional channels, such as radio broadcasts and Information, Education, and Communication materials such as posters, were also considered valuable options.

-Principle 9 Governance

To maintain the group and foster group cohesion, we co-designed terms of reference and group rules /norms. Key aspects included:

- The group is a closed group: all members must be living with a serious illness and receiving care from Mulago hospital, Mildmay Uganda or Kawempe Home Care. No new members will be added over the four years of operation.
- The group's purpose, governance structure, mode of operation, membership maintenance, and when the group would be dissolved were clearly defined (see Appendix 1 for details).

Discussion

We aimed to collaborate with children and young people to co-design processes for their engagement and involvement in palliative care research.

Through this co-design process, we identified specific activities throughout the research process where children's input is valuable, such as the reviewing of research information materials, including consent and assent forms. These entry points serve as gateways into increased engagement and involvement of children and young people in palliative care research that directly impacts their care.

Evidence shows that engaging children and young people in research processes leads to more child-centred and child friendly processes and positive engagement and involvement [17]. This is in line with United Nations conventions on the rights of children which emphasises the importance of empowering children and young people to use their voices and listening to them by providing developmentally appropriate information to empower them to participate in decisions impacting their lives (Articles 12-15, Article 17)[18].[Convention on the Rights of the Child http://www.unicef.org/crc/].

Our study contributes practical evidence on structuring meetings and engagements with children and young people as part of community engagement and involvement. Paying special attention to the need for play as part of the agenda reinforced our previous findings that play is a significant aspect of life for children and young people living with life limiting and life threatening illnesses [19].

Throughout our engagement activities, we worked closely with the multi-disciplinary team of children health professionals and invited parents and caregivers. The involvement of a multi-disciplinary team in the engagement proved especially valuable during smaller group breakout sessions, where each group was facilitated by a team member to support meaningful discussion and participation.

The approach of working together in a group enabled rapport and the building of trust, where young people felt comfortable engaging and sharing their views in a safe environment in which every group member was living with a serious illness and the co-facilitators were palliative care providers. We noted that the presence of caregivers for those who wished to have them, added an extra layer of safety, as participants could consult them on certain issues, making decision-making easier. This alliance worked well and supports the child-centred care framework, which places the family at the centre of care.

Regarding group dynamics, our engagement shows that for a group to function effectively, its formation should be underpinned by a clear framework outlining the group's purpose, roles, and inclusion and exclusion criteria. Working with people who have shared experiences improves group cohesion and engagement. Establishing and agreeing on the mode of operation such as the types of activities, frequency of meetings, and other logistic details helped catalyse group involvement and shaped how the group would operate and remain active [20]. A group without clear objectives, agreed upon regulations, and a defined leadership structure, may struggle to achieve its intended goals.

In line with the NIHR principle of facilitating power sharing, we found that having democratically elected leaders to represent the members of the child advisory council, (a council that would guide the parent study research team to effectively engage children and young people in their research) improved both coordination, and communication. These leaders effectively navigated coordination and communication to group members, making the mobilization easier and more efficient.

Our initial work is already demonstrating positive benefits for engaging children and young people in research. For example, while refining the African version of the Children's Palliative Care Outcome Scale, the young people highlighted the importance of focusing on the intensity of pain and other symptoms, as this helps them express their level of associated distress, which is a cornerstone of patient-centred palliative care. They also proposed the inclusion of key symptoms the project team had not considered regarding overeating or overfeeding. They attended our cross-national expert meeting to improve the psychometric properties of the tool and were able to engage well. These valuable contributions have directly shaped the current version of the scale. For this engagement to work well, the ethics committee recommended that we have a nurse and doctor on duty in case any of the children and young people gets a medical emergency. This may add an extra layer of complexity in terms of logistics but it is good for risk management.

Our findings are consistent with reports from the UK, where the involvement of children and young people in research has provided unique and useful ideas on the design and implementation of research projects [21].

Our findings demonstrate that children are capable of participating in the design and development of measurement tools [22]. For example, engaging and involving children and young people in palliative care research has highlighted concerns of delayed cognitive development [15] and its impact on their social and public lives.

This study offers practical guidance on where along the research process pathways it is possible to effectively engage children and young people. It presents child-friendly agendas to guide engagements during meetings, strategies for effective communication, and child-friendly options for results sharing. Most importantly, best practices are co-designed with young people. The study also provides evidence on how to meaningfully engage young people in research, and how to keep the child advisory groups active for continued engagements throughout research processes. We propose that these Africa-specific principles are considered and implemented alongside broader global perspectives on child engagement in palliative care research[17]. Early results indicate positive effects from engaging and involving young people in paediatric palliative care research, even in the initial phases. The Children and young people who participated in this activity identified some training needs which had to be addressed. We argue that if children and young people express some training needs, then it is incumbent on the study team to ensure that these needs are addressed to empower them to engage more effectively. This could call for some additional costs though.

Conclusion

Using a co-design approach, we developed child-centred principles for engaging and involving children and young people in palliative care research, and have subsequently implemented several recommended practices proposed by the children themselves. This made our research processes more acceptable and responsive to the needs of children and young people. The processes are aligned with the NIHR framework, and when effectively implemented, will lead to meaningful engagement and involvement of children and young people in palliative care research.

Abbreviations

CEI -Community Engagement and Involvement

NIHR- National Institute for Health and Care Research

Declarations

This study was conducted in accordance with the Declaration of Helsinki. Ethical approval to conduct the study was obtained from Mildmay Uganda Research and Ethics Committee (Ref: 0107-2023). Assent was sought from all participating young people and consent was sought from their guardians. Informed consent was sought from all participating adults.

Consent for publication

We have not included personal information

Availability of data and materials

Data and study materials can be accessed by contacting the authors

Competing interests

The authors declare that they have no competing interests

Funding

This study was funded by the National Institute for Health and Care Research-GHRUG NIHR134440, for the programme “GHAP: Global Health & Palliative Care”.

EN, LF, RH Writing (Original Draft Preparation) Writing (Review and Editing); Visualization.

DH, AN, EN, EN Project Administration; Investigation; Supervision.

EN, LF, RH, Formal Analysis; Writing (Original Draft Preparation); Writing (Review and Editing).

EN, LF, RH, CE, EL, ETK, JN, YK, JK, AN, MM, Conceptualization; Methodology; Writing (Review and Editing).

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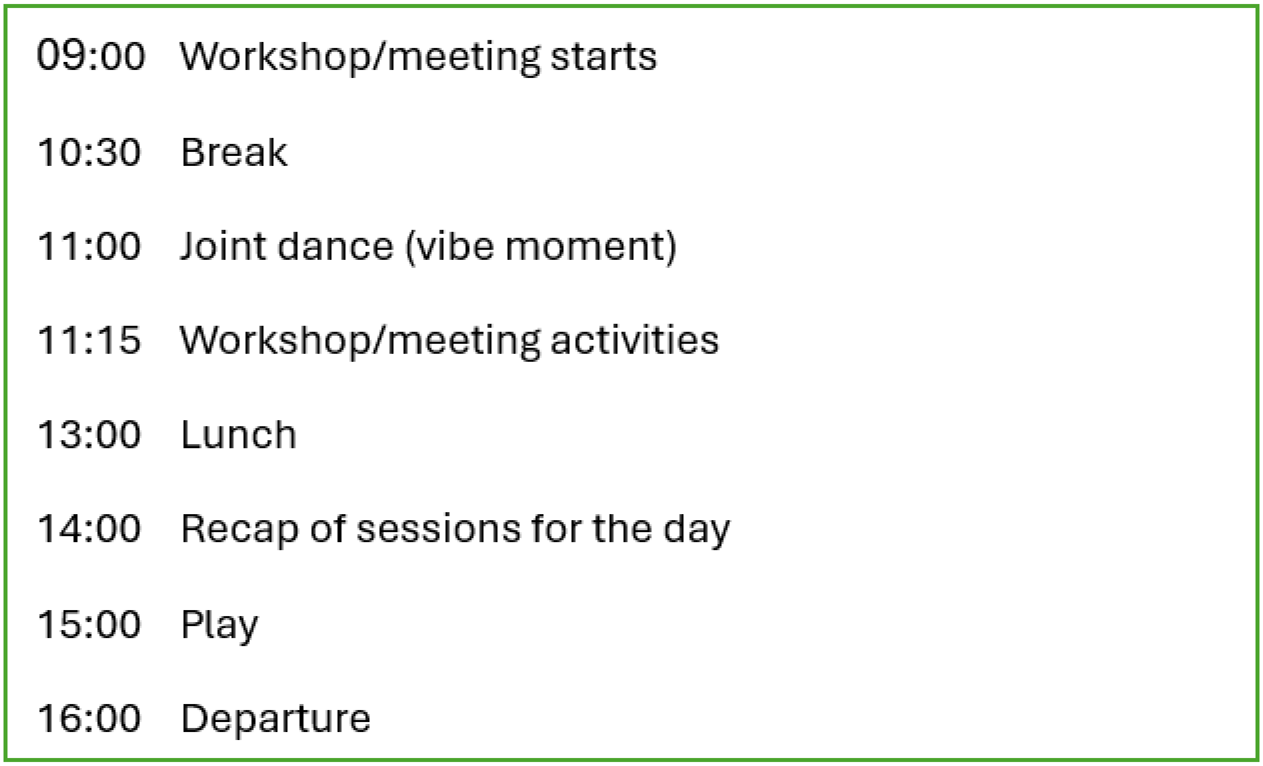
Figures



09:00	Workshop/meeting starts
10:30	Break
11:00	Joint dance (vibe moment)
11:15	Workshop/meeting activities
13:00	Lunch
14:00	Recap of sessions for the day
15:00	Play
16:00	Departure

Figure 1

A co-designed agenda for a workshop involving young people

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Appendix1.docx