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Abstract
This deliverable provides the ethical charter for the CLiViE project

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## About CLiViE

The Cultural Literacies' Value in Europe (CLiViE) project develops and applies a Theory of Change (ToC) methodology and Social Return on Investment (SROI) framework to increase our understanding of the value of cultural literacy through arts-based education on social cohesion. It will be delivered through four main phases: it 'maps' arts-based education within the context of cultural literacy learning across different learning environments and over different stages of a young person's education; it 'evaluates' arts-based education to help identify and assess their actual outputs and outcomes; it 'values' arts-based education activities through calculating its impact to further contribute to our understanding of the 'where', 'when', 'what' and 'how' young people's cultural literacies are developed, and differentiated in various learning environments; and it 'practices' pedagogies through developing an innovative set of practices and materials to support art-based educators to develop social justice and inclusion and improve the lives of young people through collaborative pedagogy. It has been designed to meet the three main research outcomes of the work programme topic: the ToC methodology and SROI framework for cultural literacies will directly increase our understanding of the value of cultural literacy on social cohesion; the evidencing of value in arts-based education and the collaborative pedagogy practices in cultural literacy through the co-creation of communities of practice (COPs) and a professional development programme (PDP) for arts educators will support the targeted commissioning of activities that will increase cultural literacy in Europe; and the innovative methodology for data gathering (and engaging) through emotional cartography allows young people to find a voice through more effective initiatives to foster cultural literacy around European cultures. CLiViE is funded under the call topic HORIZON-CL2-2023-HERITAGE-01-07 - Promoting cultural literacy through arts education to foster social inclusion, and brings together a multidisciplinary team from thirteen partners across eight countries:

HELSINGIN YLIOPISTO (Coordinator), Finland  
UNIVERZITA KARLOVA, Czechia  
STICHTING DEFENCE FOR CHILDREN INTERNATIONAL NEDERLAND - ECPAT NEDERLAND,  
Netherlands  
DAUGAVPILS UNIVERSITATE, Latvia  
JULIAN COCHRAN FOUNDATION, Poland  
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## 1. Introduction

The Cultural Literacies' Value in Europe (CLiViE) project develops and applies a Theory of Change (ToC) methodology and Social Return on Investment (SROI) framework<sup>1</sup> to increase our understanding of the value of cultural literacy through arts-based education on social cohesion.

Researching issues related to social cohesion and young people, especially if affected by inequalities, raises issues around participant recruitment and visibility and the handling of sensitive personal data. It also raises issues concerning affected groups' access to official information about projects that target their learning environments.

This deliverable (D8.1) provides the ethical charter for the CLiViE project. It ensures that the research activities are aligned to the core ethical values of the CLiViE project and Horizon Europe more generally.

At a macro level the ethical integrity of our research and its results are in accord with the following: Declaration of Helsinki in its latest version; the charter of fundamental rights of the EU (2000/C 364/01); the principles included in the Oviedo Bioethics Convention; and EU regulation 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of persons with regard to the processing of personal data and on the free movement of such data.

However, at a national level the ethical integrity of research is likely to be regulated not by a legal framework but through recommendations and/or guidance from respective, *inter alia*, research and scientific bodies. In addition, definitions of what constitutes a 'minor' and from whom consent is required will also vary in different national contexts within the CLiViE partnership. Accordingly, **the fundamental principle underpinning this ethical charter**

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<sup>1</sup> A Theory of Change is a methodology to promote social change through defining long-term goals and then mapping back to identify necessary preconditions. Social Return on Investment is an outcomes-based measurement tool that helps organisations to understand and quantify the social, environmental and economic value they are creating.

**centres on the notion of the primacy of these national recommendations and/or guidance.**

On a practical level, then, **the thirteen partners will seek ethical guidance and clearance from their respective national bodies and organisations for the work they will undertake in the CLiViE project.**<sup>2</sup> This is important given the need to respect national and local best practice, principles and regulations, within a European context.<sup>3</sup> It is also important given the need to take into account local conditions related to recruiting research participants in the development and delivery of the pilot case studies (WP3, WP4 and WP5).

This ethical charter will be overseen by the CLiViE project coordinator within the governance framework of the General Assembly and the Ethics Review Board decision of the University of Helsinki (see **Annex 1**). The University of Helsinki works within a national framework created by the Finnish Code of Conduct for Research Integrity and Procedures for Handling Alleged Violations of Research Integrity in Finland.<sup>4</sup> This is aligned to the European Code of Conduct for Research Integrity, and covers eight areas of scientific activity:

- The research environment
- Training, supervision and mentoring
- Research procedures
- Safeguards and agreements
- Data practices and management
- Collaborative working
- Authorship, publishing and dissemination
- Reviewing and evaluating.

All the CLiViE project partners are familiar with good practice in these research practices. In addition, the University of Helsinki, has appointed an ethical mentor outside of the project team (Professor Erika Löfström) to be consulted on relevant ethical issues related to the research.

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<sup>2</sup> See page 16 of the CLiViE proposal.

<sup>3</sup> The timing for when partners apply for ethical clearance is also determined by local contexts. It is possible that this may be done in stages as the project develops.

<sup>4</sup> [https://tenk.fi/sites/default/files/2023-11/RI\\_Guidelines\\_2023.pdf](https://tenk.fi/sites/default/files/2023-11/RI_Guidelines_2023.pdf)

Critically, issues related to data are addressed in the Data Management Plan (D 8.2). This plan broadly covers the following: documentation and metadata, resources and responsibilities, ethical and legal compliance, storage during the research project, and opening, publishing and archiving. It is based on data management guidance from the University of Helsinki and is aligned to Horizon Europe requirements. Issues related to intellectual property covering any artistic works, such as the maps of meaning, are also addressed in D8.2. This is important given the unique ambitions around the CLiViE project which point to potential tensions between framing research on arts-based education and art and culture more generally,<sup>5</sup> and the need to maintain ‘artistic freedom’ as recently highlighted by the Council of Europe.<sup>6</sup>

The General Assembly has also agreed that to ensure that relevant ethical issues are fully embedded into the CLiViE project delivery that the entire Executive Board will be involved to ensure compliance with the ethical principles of research in Social Sciences and Humanities (SSH) rather than in a separate body.<sup>7</sup> This management structure will also include relevant issues related to gender that may emerge in the delivery of the project.

## **2. Target groups and recruitment**

At the heart of the CLiViE project is the need to work with young people and the recognition of structural inequalities and polarisation in Europe.

For some of the pilot case studies we will focus on young people experiencing overlapping disadvantages in different areas and to differing degrees. Based on guidance from the Erasmus+ programme,<sup>8</sup> this includes groups of young people that may experience the following:

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<sup>5</sup> Manning, E. (2015). Against method. In *Non-representational methodologies* (pp. 52-71). Routledge.

<sup>6</sup> <https://www.coe.int/en/web/culture-and-heritage/-/free-to-create-report-on-artistic-freedom-in-europe>

<sup>7</sup> See D8.3 (Minutes of first General Assembly meeting)

<sup>8</sup> European Commission (2019). *Erasmus + Programme Guide*. European Commission.

- Disability (i.e. participants with special needs) - people with mental (intellectual, cognitive, learning), physical, sensory or other disabilities;
- Educational difficulties - young people with learning difficulties; early school-leavers; low qualified adults; young people with poor school performance;
- Economic obstacles - people with a low standard of living, low income, dependence on social welfare system or homeless; young people in long-term unemployment or poverty; people in debt or with financial problems;
- Cultural differences - immigrants or refugees or descendants from immigrant or refugee families; people belonging to a national or ethnic minority; people with linguistic adaptation and cultural inclusion difficulties;
- Health problems - people with chronic health problems, severe illnesses or psychiatric conditions;
- Social obstacles - people facing discrimination because of, for example, gender, age, ethnicity, religion, sexual orientation, disability; people with limited social skills or anti-social or risky behaviours; people in a precarious situation; (ex-)offenders, (ex-)drug or alcohol abusers; young and/or single parents; orphans; and
- Geographical obstacles - people from remote or rural areas; people living in small islands or in peripheral regions; people from urban problem zones; people from less serviced areas (limited public transport, poor facilities).

The CLiViE project is also informed by the ‘Convention on the Rights of the Human Child’ and in particular Article 12 which contains the right of the child to be heard. This is also called the right to participation: ‘States Parties shall assure to the child who is capable of forming his or her own views the right to express those freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.’ Accordingly, meaningful participation, such as through the co-creation of ‘measuring what matters’, is at the heart of the CLiViE project and one of the general comments from the Committee on the Rights of the Child includes nine guiding principles for meaningful children and youth participation. Issued in 2009 it covers the following:<sup>9</sup>

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<sup>9</sup> See summary report from the CLiViE ‘Listening to young people and their voices’ peer-to-peer meeting held in Leiden on 23 May 2024.



- Transparent and informative - children must be provided with full, accessible, diversity-sensitive and age-appropriate information about their right to express their views freely and their views to be given due weight, and how this participation will take place, its scope, purpose and potential impact;
- Voluntary - children should never be coerced into expressing views against their wishes and they should be informed that they can cease involvement at any stage;
- Respectful - children's views have to be treated with respect and they should be provided with opportunities to initiate ideas and activities. Adults working with children should acknowledge, respect and build on good examples of children's participation, for instance, in their contributions to the family, school, culture and the work environment. They also need an understanding of the socio-economic, environmental and cultural context of children's lives. Persons and organizations working for and with children should also respect children's views with regard to participation in public events;
- Relevant - the issues on which children have the right to express their views must be of real relevance to their lives and enable them to draw on their knowledge, skills and abilities. In addition, space needs to be created to enable children to highlight and address the issues they themselves identify as relevant and important;
- Child-friendly - environments and working methods should be adapted to children's capacities. Adequate time and resources should be made available to ensure that children are adequately prepared and have the confidence and opportunity to contribute their views. Consideration needs to be given to the fact that children will need differing levels of support and forms of involvement according to their age and evolving capacities;
- Inclusive - participation must be inclusive, avoid existing patterns of discrimination, and encourage opportunities for marginalized children, including both girls and boys, to be involved. Children are not a homogenous group and participation needs to provide for equality of opportunity for all, without discrimination on any grounds. Programmes also need to ensure that they are culturally sensitive to children from all communities;
- Supported by training - adults need preparation, skills and support to facilitate children's participation effectively, to provide them, for example, with skills in listening,

working jointly with children and engaging children effectively in accordance with their evolving capacities. Children themselves can be involved as trainers and facilitators on how to promote effective participation; they require capacity-building to strengthen their skills in, for example, effective participation awareness of their rights, and training in organizing meetings, raising funds, dealing with the media, public speaking and advocacy;

- Safe and sensitive to risk - in certain situations, expression of views may involve risks. Adults have a responsibility towards the children with whom they work and must take every precaution to minimize the risk to children of violence, exploitation or any other negative consequence of their participation. Action necessary to provide appropriate protection will include the development of a clear child-protection strategy which recognizes the particular risks faced by some groups of children, and the extra barriers they face in obtaining help. Children must be aware of their right to be protected from harm and know where to go for help if needed;
- Accountable - a commitment to follow-up and evaluation is essential. For example, in any research or consultative process, children must be informed as to how their views have been interpreted and used and, where necessary, provided with the opportunity to challenge and influence the analysis of the findings. Children are also entitled to be provided with clear feedback on how their participation has influenced any outcomes. Wherever appropriate, children should be given the opportunity to participate in follow-up processes or activities. Monitoring and evaluation of children's participation needs to be undertaken, where possible, with children themselves.

In specific terms, all data collection activities will take place in safe environments for the participants and the recruitment of participants will follow six key principles drawn from international best practice:<sup>10</sup>

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<sup>10</sup> As well as the Finnish Code of Conduct on Research Integrity also see the ESRC's Framework for research ethics (<https://www.ukri.org/councils/esrc/guidance-for-applicants/research-ethics-guidance/framework-for-research-ethics/our-core-principles/#contents-list>)

- Research should aim to maximise benefit for individuals and society and minimise risk and harm;
- The rights and dignity of individuals and groups should be respected;
- Wherever possible, participation should be voluntary and appropriately informed;
- Research should be conducted with integrity and transparency;
- Lines of responsibility and accountability should be clearly defined with partner organisations; and
- Independence of research should be maintained and where conflicts of interest cannot be avoided they should be made explicit.

The CLiViE project aims to have a direct impact on at least 560 young people through WP3 and WP4. The CLiViE partner will therefore seek to ensure the following:

- Ensure an equitable and appropriate selection of research participants. For every activity involving research participants, the project partners, supported by the Coordinator and WP leads, will agree on the identification of eligible participants, specific criteria and procedures for the recruitment.
- The recruitment of participants will be respectful with the research participants. Potential participants will receive complete and appropriate information about the study and their own involvement. This is especially important given that the CLiViE project may work with young people who will have been marginalised from (or by) research activities.
- The use of assent/consent forms will allow participants from withdraw at any time. Ensuring anonymity and confidentiality in regard to the use of personal and other data will also be guaranteed through the Data Management Plan (see D 8.2).
- Any participation in research will be voluntary and participants will be able to choose without pressure and coercion if they agree to take part in the research. Assent/Consent forms will reflect this acceptance and will be signed prior to the collection of data. Furthermore, these forms will include a statement explaining that participants will be free to withdraw their participation at any time, without giving justification or suffering negative consequences.

### 3. Procedures

As noted above responsibility for the appropriate ethics review and monitoring lies with the University of Helsinki. The University of Helsinki Ethical Review Board in Humanities and Social and Behavioural Sciences has already undertaken a review and given approval (see **Annex 1**). This follows on from the Ethics Review self-assessment that was undertaken by the Coordinator as part of the Horizon Europe application process (see **Annex 2**).<sup>11</sup>

Critically, as noted above, the thirteen partners of the CLiViE project will seek ethical guidance and clearance from their respective national bodies and organisations for the work they will undertake.<sup>12</sup> When it comes to working with young people in the CLiViE project the Executive Board has agreed that voluntary participation is a key aspect of the CLiViE ethical charter and throughout the recruitment process researchers will ensure that potential participants can decide their level of involvement. To further support this we will ensure the following:

- All conversations between researchers and potential participants about the possibility of participating in the research will occur in a place where the participants feel comfortable and safe in order to avoid any possible coercion and to ensure that the decision has been taken with absolute freedom;
- Researchers will inform participants that they will not receive any economic reward and all possible risks and benefits of participating will be discussed;
- The recruitment process will not be conducted by someone who may have an undue influence on potential participants; and
- The language employed in the pilots will be appropriate and accessible to participants and reflect the local conditions where the work is being carried out.

In seeking ethical guidance and clearance, the thirteen partners will also have to devise their own assent/consent forms to meet local conditions and national contexts. However, at a

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<sup>11</sup> The question, 'Does this activity involve human participants' the box should be ticked 'Yes'.

<sup>12</sup> See page 16 of the CLiViE proposal.

general level potential participants need to be provided information about the project and complete and sign an assent/consent form to participate in the project. Any participant (or parent/guardian) who does not complete and sign the form will not be able to participate. Some of the practical issues in relation to assent/consent forms that partners need to consider include:<sup>13</sup>

- Forms will be either in paper or electronic format depending on how they are collected. But participants will need to complete and sign a written document;
- Forms will be translated into national languages, and they will be simple, clear and direct to avoid misunderstanding;
- Potential participants need to be given who have enough time to read the information and form, consider their options and review the document; and
- When recruiting minors<sup>14</sup>, parents/legal guardians must be involved and sign.

It is also important to ensure that all written material and/or forms shared with potential participants meet the necessary project and European Union branding as stipulated in Article 17 of the Grant Agreement.

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<sup>13</sup> Some information to include in these forms is provided in Annex 3. However, these need to be tailored to local and national contexts and audiences.

<sup>14</sup> Typically the definition of a minor is under the age of 18. But this can vary depending on individual country contexts and needs to be adjusted accordingly.

# Annex 1: Review Board Decision

University of Helsinki Ethical Review Board in Humanities and Social and Behavioural Sciences

Kristiina Kumpulainen

To whom it may concern,

Kristiina Kumpulainen at the University of Helsinki has asked the Research Ethics Committee in the Humanities and Social and Behavioural Sciences of the University of Helsinki to provide a description of the ethical review system for research in Finland.

In Finland, research with human participants must comply with the guidelines of the Finnish National Board on Research Integrity TENK<sup>1</sup> [The ethical principles of research with human participants and ethical review in the human sciences in Finland. Finnish National Board on Research Integrity TENK guidelines 2019 \(pdf\)](#).

The University of Helsinki has undertaken to comply with TENK's guidelines. The guidelines do not cover medical research as defined by law (Medical Research Act 488/1999) or other research designs where ethical review is a separate obligation laid down by law.

According to the guidelines, research is to be conducted in such a way that the dignity and autonomy of human research participants is respected, and the research does not cause significant risks, damage or harm to research participants, communities, or other subjects of research.

Ethical review is to be carried out prior to gathering data, if the research contains one or more of the following factors:

1. Participation in the research deviates from the principle of informed consent. Participation is not, for example, voluntary, or the subject is not given sufficient or correct information about the research.
2. The research involves intervening in the physical integrity of research participants.
3. The focus of the research is on minors under the age of fifteen, without separate consent from a parent or carer, or without informing a parent or carer in a way that would enable them to prevent the child's participation in the research.
4. Research that exposes participants to exceptionally strong stimuli.
5. Research that involves a risk of causing mental harm that exceeds the limits of normal daily life to the research participants or their family members or others closest to them.
6. Conducting the research could involve a threat to the safety of participants or researchers or their family members or others closest to them.

**If none of the above factors is met, ethical review is not required.**

**In Finland, neither legislation nor TENK's guidelines require ethical review by an ethics committee for research based purely on public and published data, registry and documentary data or archive data.**

Helsinki, February 26, 2024



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Aura Kivilaakso  
Research Integrity Coordinator, University of Helsinki

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<sup>1</sup> The Finnish National Board on Research Integrity TENK is an expert body appointed by the Ministry of Education and Culture and tasked with promoting research integrity and preventing research misconduct in Finland. Further information about the ethical review system in Finland is available at [www.tenk.fi](http://www.tenk.fi).

## Annex 2: Ethics Table

<b>1. HUMAN EMBRYONIC STEM CELLS AND HUMAN EMBRYOS</b>			<b>Page</b>
Does this activity involve Human Embryonic Stem Cells (hESCs)?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity involve the use of human embryos?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>2. HUMANS</b>			<b>Page</b>
Does this activity involve human participants?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity involve interventions (physical also including imaging technology, behavioural treatments, etc.) on the study participants?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity involve conducting a clinical study as defined by the Clinical Trial Regulation (EU 536/2014)? (using pharmaceuticals, biologicals, radiopharmaceuticals, or advanced therapy medicinal products)		<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>3. HUMAN CELLS / TISSUES (not covered by section 1)</b>			<b>Page</b>
Does this activity involve the use of human cells or tissues?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>4. PERSONAL DATA</b>			<b>Page</b>
Does this activity involve processing of personal data?		<input checked="" type="radio"/> Yes <input type="radio"/> No	15
If <b>YES</b> :	Does it involve the processing of special categories of personal data (e.g.: sexual lifestyle, ethnicity, genetic, biometric and health data, political opinion, religious or philosophical beliefs)?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
	If <b>YES</b> : Does it involve processing of genetic, biometric or health data?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
	Does it involve profiling, systematic monitoring of individuals, or processing of large scale of special categories of data or intrusive methods of data processing (such as, surveillance, geolocation tracking etc.)?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity involve further processing of previously collected personal data (including use of preexisting data sets or sources, merging existing data sets)?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
Is it planned to export personal data from the EU to non-EU countries?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
Is it planned to import personal data from non-EU countries into the EU or from a non-EU country to another non-EU country?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity involve the processing of personal data related to criminal convictions or offences?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>5. ANIMALS</b>			<b>Page</b>
Does this activity involve animals?		<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>6. NON-EU COUNTRIES</b>			<b>Page</b>

Will some of the activities be carried out in non-EU countries?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
In case non-EU countries are involved, do the activities undertaken in these countries raise potential ethics issues?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Is it planned to use local resources (e.g. animal and/or human tissue samples, genetic material, live animals, human remains, materials of historical value, endangered fauna or flora samples, etc.)?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Is it planned to import any material from non-EU countries into the EU or from a non-EU country to another non-EU country? For data imports, see section 4.	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Is it planned to export any material from the EU to non-EU countries?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity involves <a href="#">low and/or lower-middle income countries</a> ? (if yes, detail the benefit-sharing actions planned in the self-assessment)	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Could the situation in the country put the individuals taking part in the activity at risk?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>7. ENVIRONMENT, HEALTH and SAFETY</b>		<b>Page</b>
Does this activity involve the use of substances or processes that may cause harm to the environment, to animals or plants (during the implementation of the activity or further to the use of the results, as a possible impact)?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity deal with endangered fauna and/or flora / protected areas?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
Does this activity involve the use of substances or processes that may cause harm to humans, including those performing them (during the implementation of the activity or further to the use of the results, as a possible impact)?	<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>8. ARTIFICIAL INTELLIGENCE</b>		<b>Page</b>
Does this activity involve the development, deployment and/or use of Artificial Intelligence? (if yes, detail in the self-assessment whether that could raise ethical concerns related to human rights and values and detail how this will be addressed).	<input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>9. OTHER ETHICS ISSUES</b>		<b>Page</b>
Are there any other ethics issues that should be taken into consideration?	<input type="radio"/> Yes <input checked="" type="radio"/> No	

I confirm that I have taken into account all ethics issues above and that, if any ethics issues apply, I will complete the ethics self-assessment as described in the guidelines [‘How to Complete your Ethics Self-Assessment’](#).

X



## Annex 3: Suggested headings and text for assent/consent forms

### Individual<sup>15</sup>

..... (participant's name

assent/consent to participate in a study conducted by

I am aware that participation in the Cultural Literacies' Value in Europe (CLiViE) project is entirely voluntary. I may withdraw my participation at any time and have the data obtained through this study returned to me, removed from the database or deleted.

The following points have been explained to me:

- The purpose of this study
- I will be asked to
- What the potential risks or inconveniences are
- The entire duration of my participation will be approximately
- The data obtained during this study will be processed anonymously and will therefore not be able to be traced back to me.
- The researcher will answer any questions I have about this study, now or at any time while the study is ongoing.
- I have been provided with the contact details for the researcher

Date:

Researcher's signature:

Date:

Participant's (or parent/guardian) signature:

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<sup>15</sup> Partners will need to design their own assent/consent forms that meet local condition and national guidelines. These forms will need a simple and brief description of the project. The following is an example: 'The Cultural Literacies' Value in Europe (CLiViE) project is funded by the Horizon Europe programme of the European Commission and aims to research the value of arts-based education on children and young people'. Necessary European Union branding as stipulated in Article 17 of the Grant Agreement must also be included in any assent/consent forms.

## Focus groups<sup>16</sup>

EU Grant Agreement number: 101132285

Project acronym: CLiViE

Project title: Cultural Literacies' Value in Europe

Informed assent/consent for the focus group If you wish to participate in the research, we ask that you carefully read and answer the questions included in this Informed Consent form: (Please mark the answer that you think is correct)

Have you understood all the information included in the project information sheet and have you been provided with a copy of it?	YES /NO
Have you had the opportunity to ask questions about the research?	YES /NO
Have you understood that you are free to leave the interview without any possible prejudice?	YES /NO
Will you receive any type of compensation for participating?	YES /NO
Have you understood that your data will always be kept anonymous and confidential and you agree?	YES /NO
Have you understood that the data from this interview, always anonymous, will be used for publications and communications in scientific or informative forums in order to provide evidence to society?	YES /NO
Have you understood that you are being asked to maintain confidentiality about the interview and the research itself while the research is ongoing?	YES /NO

Date:

Researcher's signature:

Date:

Participant's (or parent/guardian) signature:

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<sup>16</sup> See footnote 15