Engagement with Children and Young People in Studying Well-Being: Results from the European Cohort Development Project (ECDP)

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Introduction
The European Cohort Development Project (ECDP)

• Highlights the importance of child-centered approaches to studying well-being:

• Survey measures, ethical issues, format and ways of implementation should be developmentally valid and appropriate for children and youth as survey participants

• Children and young people should be the key stakeholders in the interpretation and use of survey results
Benefits of engaging CYP in the research design and process

CYP

• Improve practical experience with the realization of research
• Ability to manage, organize and cooperate with managerial skills
• Enhancing youth civic engagement
• Better understanding of youth problems and their needs

Researchers

• Sets of recommendations, procedures and methods
• Examples and guides to manage workshops, interviews and focus groups
• Improving leadership, training for young participants, providing secure environment for collaboration
• Contribute to practical solutions
• Improve youth – researchers – stakeholders relationships

This project has received funding from the European Union’s Horizon 2020 Research and Innovation programme under the Agreement no 777449
CYPAG: Children and Young Person’s Advisory Groups

CYPAG

• A formal mechanism to engage children and young people to share their understandings and expectations about their well-being and their future
• Continuous involvement of a small number of children and young people

• In order to ensure children and young people’s engagement and coproduction in the ECDP (the Work Package 6), we set up two Children and Young Person’s Advisory Groups (CYPAGs) in two countries (UK and Croatia)
• This collaboration between youth and researchers aimed to:

  ▪ Ensure that children and young people have a formal distinguished role in ECDP
  ▪ Inform children and young people about the ECDP & EuroCohort
  ▪ Seek feedback from children and young people on different relevant issues (e.g. research tools, ethics, videos).
The main goals

• The main goal of the CYPAG workshops conducted in the UK and Croatia was to gain novel insights:

a) How children and young people understand well-being concepts?

b) How children and young people understand research-related ethical issues (e.g. informed consent, privacy issues, data protection)? What do they recommend and expect?

c) How would they like to be consulted and treated in the EuroCohort context? How they see their mission in CYPAG within the EuroCohort project?
Method
Recruitment

- The direct collaboration and personal contacts with primary and secondary schools-
  meetings with school teachers and headmaster
- The participants were given incentive (cca 15 EUR worth) at the end of each workshop
- Croatian CYPAG-some participants coming from potentially vulnerable populations, such as:
  - Minority children and young people - 3
  - Children and young people whose parents are divorced - 3
  - Children and young people from single-parent families - 2
  - Children and young people with chronic illness - 2
  - Children and young people living in poverty - 2
## CYPAG Participants

<table>
<thead>
<tr>
<th>WORKSHOP</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>AGE</th>
<th>GENDER</th>
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<tbody>
<tr>
<td>UK</td>
<td>N=22</td>
<td>N=14</td>
<td>n/a</td>
<td>12 to 15</td>
<td>Majority female (N=17)</td>
</tr>
<tr>
<td>Croatia</td>
<td>N=20</td>
<td>N=19</td>
<td>N=18</td>
<td>10 to 15</td>
<td>Majority female (N=14)</td>
</tr>
</tbody>
</table>

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Procedure

**Workshop 1**
EuroCohort and Well-being

- a) Introducing the project and the idea of CYPAG
- a) Assessing how CYPAG members understand well-being

**Workshop 2**
Ethics and privacy

- a) Discussing the ethics and privacy issues
- b) Seeking CYPAGs’ feedback on the informed consent form, privacy and data protection issues

**Workshop 3**
Final consultation

- a) Presenting and evaluating changes made from the CYPAGs’ feedback and recommendations
- b) Reflective Storytelling Workshop

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Results
1. Understandings of Well-Being

• CYPAG members defined well-being using specific and concrete terminology

• In these definitions, two main aspects of life emerged as the most important well-beings domains:

  a) The quality of social relationships, including family relations, relations with friends, being a good person and being kind to others

  b) Engagement in school, learning and interesting leisure activities

"It makes me happy when I have a sense of good relationships with my whole family, when I have no stress and when I'm good at school"
The importance of different life aspects for well-being
2. Ethics and privacy issues

• CYPAGs’ opinion and suggestions about ethics:
  • How to protect children’s rights during EuroCohort project?
  • How to ensure children’s anonymity in longitudinal research?
  • How to facilitate children’s participation at the EuroCohort ethics committee?

• Many CYPAG participants said that they are not familiar with children and young people’s rights, especially in the area of research

  “We are not really aware of the rights “
  “I did not know that I can quit at any time “
Informed consent

• When discussing consent forms, children understood the importance of informed consent and they knew the meaning of confidentiality and anonymity

  “Anonymity means that our names are not known to others“

• They liked the idea to be asked for personal consent

  „This is a good thing because we are asked for opinion.“

  “I feel responsible, I have a feeling that someone wants to hear our opinion and I feel important”

  „I feel excited, important, grown up, and happy, but I also feel a little bit scared to say something wrong.”
• CYPAG agrees that researchers should first ask parents if their child can participate in the study.

• If children would like to participate but their parents decline to sign the parental consent, they would try to convince them or would try to find alternative ways to get consent.

   “I would ask my grandmother”

   “Maybe they would get angry but we could talk to them and convince them to participate”
Informed consent-first form

“We not usually asked for our signature.. So it makes me feel good”

- Too long
- Not enough colour
- Not enough pictures

“I couldn’t be bothered..”
Consent form – CYPAG’s recommendations

• Pictures
• 1 page maximum
• Bullet points
• Rounder shape
• Coloured background
• Videos

- GDPR
- Data protection
- Trust (teacher/university)
Revise Informed consent form

“I think this form is better because children of any age can read it”

- Includes the relevant information
- Shorter and therefore more readable
- Use of bullet points
Privacy

• CYPAG members associated privacy in general with mobile phones, messages, and private conversations—and thought it is very important

“Privacy protection is very, very, important”

• They also indicated that there are some issues that are so private they should not even be inquired (some UK participants thought it was ‘fair game’ to be asked anything)

“I would like to have the option to skip some questions”

“It would be great if we had the option to choose not to talk about some topics”

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Data protection

• Parents should not be present during interviews for any study-their presence would influence their answers on some topics

  “They should not be present because we would not tell the truth”

• When asked about privacy in answering questionnaire in front of researchers, CYPAG stated that they generally felt comfortable and secure

  “Yes, the atmosphere is pleasant, and the researchers are very friendly”

• Regarding the dissemination of the survey results, CYPAG mentioned several options such are: social networks, video clips, brochures, Power-point presentations, TV commercials.
CYPAG suggestions for data and privacy protection, and fostering honest answers in surveys:

- Interview with just one person or Using paper-pencil method
- Having the option to skip questions/topics in the survey
- No parents/guardians, teachers etc. during survey interviews
- Researchers/Interviewers should acknowledge and accept their opinions and experiences without judgment
- Researchers/Interviewers should be understanding and respectfull
3. CYPAG role within the EuroCohort context

• Workshop & Reflective Storytelling Session
  • Aimed to support CYPAG members to plan and record an individual short reflective story (e.g. audio or video, 30 seconds – 1 minute approx.)
  • Provides insights into how CYPAGs should be organized, delivered and utilized within research projects.

• CYPAG members stated that EuroCohort research project is beneficial, important, and useful. They would like to participate in well-being surveys:
  • If they would feel that is useful
  • If their voices and opinions would be respected
  • They would like to be asked about parents, friends, leisure, and their everyday lives.

"Happiness research is important because you listen to us"
CYPAG participants showed that they liked the project as well as their role in it

“My role was important, I think I helped make it easier to find happiness for children”

“My mission was to give the researchers a view from children's eyes and to help them and other children that will participate in future research”
Conclusions
• In line with existing research (e.g. Tadić Vujčić et al., 2019), well-being is typically understood in terms of:

  a) The quality of social relationships (family and friends)
  b) Engagement in school, learning and interesting leisure activities

• Researchers should **first ask parents if their child can participate in the study, but parents should not be present during interviews** for the study in order for children and young people to feel free and safe to talk about different topics.
• Children and young people are not sufficiently familiar with children and young people’s rights as participants in research, but they understand:
  • The importance of informed consent and like the idea that they are being asked for personal permission
  • The meaning of confidentiality and anonymity

• Informed consent should be relatively short and concise (i.e. bullet points better than long sentences, paragraphs, and descriptions) so that is readable, easy to focus and concentrate on, particularly for younger age groups.

• The consent form should include sufficient and clear information about the role and meaning of CYPAG, as well as on the activities that will take place during the CYPAG.
• Children and young people participating in research should have an option not to talk about some topics—without judgment.

• The CYPAG members all agreed that the ECDP research project is beneficial, important, and useful. They pointed out that they would like to participate in such well-being surveys if they feel that it might be useful and if they would have the opportunity to have their voices heard.

• CYPAG participants understand their mission in CYPAG and ECDP, and they liked the project as well as their role in it because it made them feel heard and important.