



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

Maja Tadić Vujčić (Institute of social sciences Ivo Pilar)

Andreja Brajša Žganec (Institute of social sciences Ivo Pilar)

Jessica Ozan (Manchester Metropolitan University)

Jaroslav Mihálik (University of Saints Cyril and Methodius)



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Introduction



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The European Cohort Development Project (ECDP)

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- 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



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Benefits of engaging CYP in the research design and process

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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



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CYPAG: Children and Young Person's Advisory Groups

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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
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- 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)



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CYPAG: Children and Young Person's Advisory Groups

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- 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).



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The main goals

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- 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?**



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Method



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Recruitment

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- 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



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CYPAG Participants

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WORKSHOP	1.	2.	3.	AGE	GENDER
UK	N=22	N=14	n/a	12 to 15	Majority female (N=17)
Croatia	N=20	N=19	N=18	10 to 15	Majority female (N=14)



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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



Results



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1. Understandings of Well-Being

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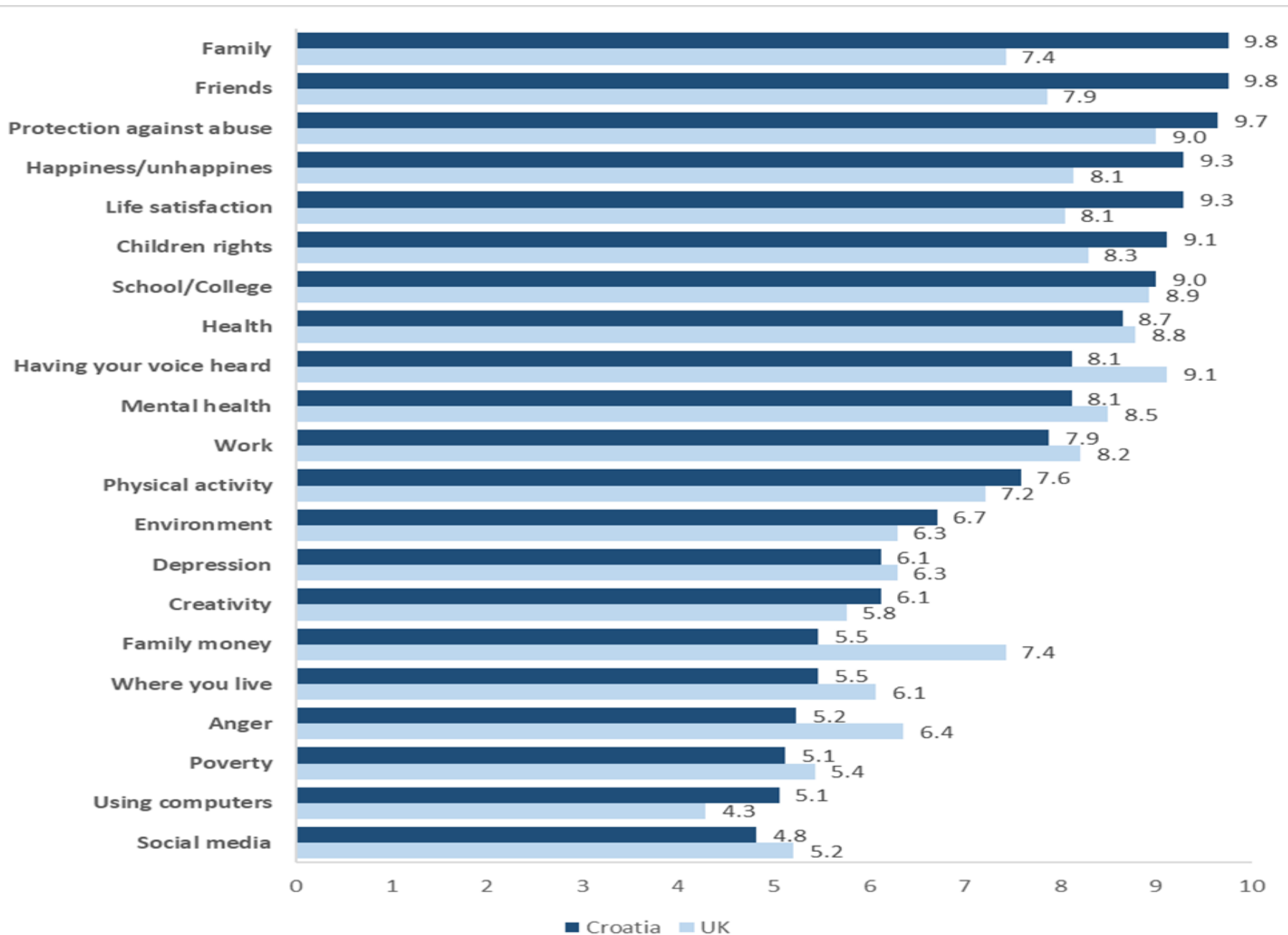
- CYPAG members defined well-being using specific and concrete terminology
- In these definitions, two main aspects of life emerged as the most important well-beings domains:

- 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

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- 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 "



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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.

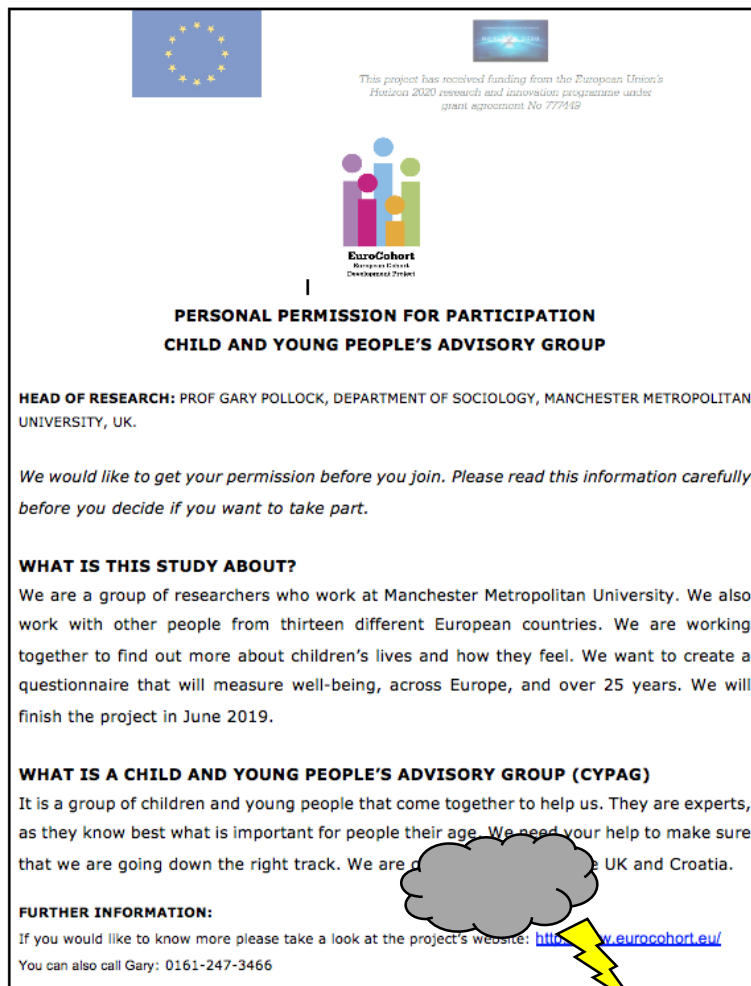
“I would ask my grandmother”



“Maybe they would get angry but we could talk to them and convince them to participate”




Informed consent-first form

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EuroCohort
European Cohort
Development Project

**PERSONAL PERMISSION FOR PARTICIPATION
CHILD AND YOUNG PEOPLE'S ADVISORY GROUP**

HEAD OF RESEARCH: PROF GARY POLLOCK, DEPARTMENT OF SOCIOLOGY, MANCHESTER METROPOLITAN UNIVERSITY, UK.

We would like to get your permission before you join. Please read this information carefully before you decide if you want to take part.

WHAT IS THIS STUDY ABOUT?

We are a group of researchers who work at Manchester Metropolitan University. We also work with other people from thirteen different European countries. We are working together to find out more about children's lives and how they feel. We want to create a questionnaire that will measure well-being, across Europe, and over 25 years. We will finish the project in June 2019.

WHAT IS A CHILD AND YOUNG PEOPLE'S ADVISORY GROUP (CYPAG)

It is a group of children and young people that come together to help us. They are experts, as they know best what is important for people their age. We need your help to make sure that we are going down the right track. We are currently working in the UK and Croatia.

FURTHER INFORMATION:

If you would like to know more please take a look at the project's website: <http://www.eurocohort.eu/>
You can also call Gary: 0161-247-3466

WHAT WILL HAPPEN?

The group will meet twice during the project. You will be invited to attend two workshops. We will show you what we are doing and will ask for your opinions.

For example, we will show you a booklet we created for children and young people and ask you if you can understand everything and if you would like to change anything. The workshops will take 3 hours 30 minutes maximum and include a lunch break. They will take place on a Saturday so they will not interfere with school or college.

CONFIDENTIALITY

This means that we will not use your name or anything that may identify you in our reports. Only the people who are there during the workshop will know what you said. We will talk to other adults about what you said only if we believe that you are in danger.


WHY TAKE PART?

Your opinions are very important to us. They will help us create a better questionnaire and better ways to explain what we are doing to other children and young people. At the end of the project, we will create a document that will show how you have helped us. To thank you for your time and opinions, you will receive a little gift at each meeting you come to.

You can decide that you do NOT want to take part in the group.

You can decide to take part in the group now and change your mind later. When we meet you for the meeting, we will remind you that you can decide to stop the meeting at any time.

SIGNING THE FORM BELOW MEANS YOU ACCEPT TO TAKE PART IN THE GROUP.

I,  _____, agree to take part in the Children and Young People's Advisory Group for the European Cohort Development Project.

Your signature

Date

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

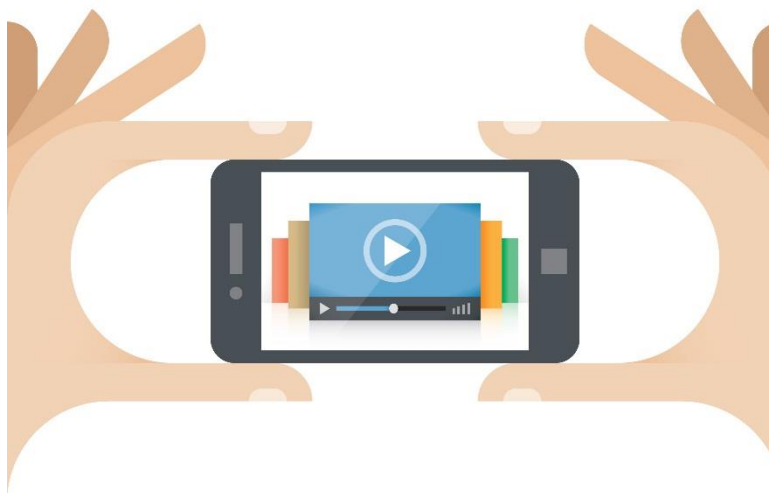
- Too long
- Not enough colour
- Not enough pictures

"I couldn't be bothered.."

Consent form – CYPAG's recommendations

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



- GDPR
- Data protection
- Trust (teacher / university)

Revised Informed consent form

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APPENDIX 2: YOUTH ADVISORS GROUP
PERSONAL PERMISSION FOR PARTICIPATION

*We would like to get your permission before you join.
Please read this information carefully before you decide if you want to take part.*

WHAT IS THIS STUDY ABOUT?

- A European project across 13 countries.
- Finding out more about children's lives and how they feel.
- Creating a questionnaire that will measure well-being, across Europe, over 25 years.
- We are having consultations with young people in the UK and Croatia.
- More info: <http://www.eurocohort.eu/>

WHAT WILL WE DO?

- Meet twice this year, on Saturdays, over 3h30 (including lunch)
- Tell you about what we are doing
- Ask for your opinion and advice on what we should keep and what we should change
- At the end of the project, you will receive a document showing you how you have helped us.

WHY TAKE PART?


- Your opinions are very important to us.
- You can help us create better questionnaires and find better ways to explain what we are doing to other children and young people.
- To thank you for your time and opinions, you will receive a £10 voucher at each workshop.

IMPORTANT THINGS TO KNOW:

- We will not use your name or anything that may identify you in our reports.
- We will talk to other adults about what you said only if we believe you are in danger
- You can decide that you do NOT want to take part in the group.
- You can decide to take part in the group now and change your mind later. You can stop at any time.


SIGNING THE FORM BELOW MEANS YOU ACCEPT TO TAKE PART IN THE GROUP

I, _____
agree to take part in the group


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Date: _____

Your signature: _____


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“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

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- 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”



- 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:

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- Interview with just one person or Using paper-pencil method
- Having the option to skip questions/topics in the survey
- No parents/guardians, techers 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

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- 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"*



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- 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 eyes and to help them and other children that will participate in future research”



Conclusions



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- 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 them 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.**

