



# Module 1

## Young Carers and Participatory Research



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### Lesson 1: Understanding Young Carers and Participatory Research

G.A. N° 2022-2-IE01-KA220-YOU-883F8363

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Welcome to our first lesson on **Young Carers and Participatory Research**.

In this lesson, we'll dive into understanding the world of young carers. In today's lesson, we'll cover:

**Who are young carers, and what experiences do they have?**

**The concept of participatory research and why it's so valuable for working with young carers.**

By the end of this lesson, you'll have a clearer picture of the challenges and strengths of being a young carer and how we can best support them through research. and advocacy.





# CHAPTER 1

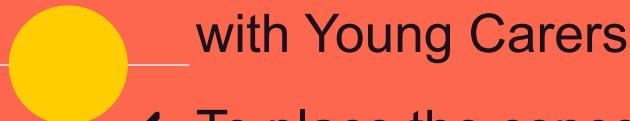


## The concept of participatory research.

### OBJECTIVES:

✓ To define Participatory Research and Its Principles

✓ To explore the benefits of Participatory Research



with Young Carers

✓ To place the concept of participatory research in the European context

✓ To clarify ethical considerations when engaging young carers in research

✓ To establish an action focus



# Participatory Research. A Definition

**Participatory research is a collaborative research methodology where those affected by an issue actively shape the entire research process. It moves beyond studying communities and empowers them to be co-creators of knowledge, leading to solutions that better address their needs.**



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# Participatory Research. Principles

- **Inclusivity:** Deliberately including those typically outside the development process.
- **Empowerment:** Empowering participants to influence research outcomes.
- **Collaboration:** Working together to co-create knowledge.



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# Participatory Research. Benefits for Young Carers

- Empowerment and Impact.
- Develops skills and confidence.
- Provides a platform to advocate for themselves and their peers.
- Leads to more relevant and effective solutions.



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# Participatory Research. Benefits for Young Carers and Beyond

- Builds youth leadership and capacity.
- Challenges stereotypes and promotes understanding of diverse experiences.
- Improves policies and service models to support young carers better.



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# Participatory Research. The European context

Participatory research aligns with broader European initiatives for Responsible Research and Innovation (RRI).

This means conducting science and research in inclusive ways, responsive to societal needs, and considering ethical implications. Working with young carers in a participatory framework directly addresses these principles.



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# Participatory Research. Ethical Considerations

This approach aligns with European initiatives for Responsible Research and Innovation (RRI), promoting inclusive, responsive, and ethical science.



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# Participatory Research. Action Orientated Focus

Participatory research shifts the focus from simply understanding the problems marginalised groups face to working alongside them for change. Young carers are involved in identifying research questions, collecting and analysing data, and using findings to advocate for improved support and policies.



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# The advantages of participatory research



- Empowerment:
  - How involving young carers in research empowers them.
  - Their active role in shaping decisions and outcomes.
- Meaningful Outcomes:
  - How participatory research leads to more relevant and impactful results.
  - Examples of positive changes achieved through participatory approaches.
- European Legislation Reference:
  - Practices.



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# Group Discussion



- What benefits can participatory research offer to young carers?
- How does it empower them?
- How might it lead to more meaningful outcomes?
- What are your insights and experiences?
- Do you have stories or examples of positive impact resulting from participatory research?



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# Case Study. Young Carers Shaping Mental Health Support



**Project Description:** A youth mental health organisation partners with a group of young carers (ages 12-18) to understand how their caregiving roles impact their mental well-being.

The goal is to co-design new support services tailored to their needs.



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# Ethical Considerations Small Group Discussions



## Objective:

To address **ethical considerations** when engaging young carers in research.



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## Quiz and Plenary

"Now that we've explored the world of young carers and participatory research, let's take a short quiz to test your knowledge.

This will help you review the key concepts we've discussed."



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# Quiz

## Question 1

Which of the following is the BEST definition of a young carer?

- A. A person under 18 who provides regular, unpaid care for a family member with a chronic illness.
- B. A child who occasionally helps with household chores due to a parent's temporary illness.
- C. A young person who volunteers at a nursing home or senior care facility.
- D. A teenager who babysits their younger siblings for a few hours a week.



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# Quiz

## Question 2

Participatory research differs from traditional research in that it:

- A. Focuses exclusively on large-scale quantitative studies.
- B. Emphasises collaboration and shared decision-making with participants.
- C. Uses only qualitative data collection methods.
- D. Never involve research participants in the data analysis phase.



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# Quiz

## Question 3

Which of the following is a potential benefit of participatory research with young carers?

- A. It can lead to more relevant and impactful research outcomes.
- B. It can empower young carers and build their self-advocacy skills.
- C. It aligns with European policies promoting inclusive research practices.
- D. All of the above.



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# Quiz

## Question 4

A critical ethical consideration when conducting participatory research with young carers is:

- A. Ensuring informed consent throughout the process.
- B. Prioritising the researcher's agenda over participants' needs.
- C. Minimising the time commitment required from young carers.
- D. Avoiding sensitive topics that might be emotionally challenging.



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# Quiz

## Question 5

Which of the following is an example of a participatory research method for young carers?

- A. Conducting a survey designed by adult researchers.
- B. Facilitating a focus group led by young carers themselves.
- C. A researcher observes young carers in their home setting without their knowledge.
- D. Interviewing teachers but not the young carers about the impact of caregiving on education.



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# Quiz Answers

*Answers:*

1) *A*

2) *B*

3) *D*

4) *A*

5) *B*



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# Module 1 Lesson 1 Review



## Key Takeaways - Young Carers & Participatory Research

- Young carers are a diverse group with unique experiences and challenges.
- Participatory research empowers young carers and leads to more impactful outcomes.
- Understanding and addressing ethical considerations is essential in participatory research with young carers.
- Collaboration is critical to conducting meaningful research that benefits young carers.





## Module 1

# Young Carers and Participatory Research



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## Lesson 2: From Identification To Engagement of Young Carers

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# Recap and Reflection

## THINK-PAIR-SHARE



### Objectives:

- To revisit key concepts from Lesson 1.
- To connect previous learning to the current lesson's focus.

In pairs, please take a few minutes to discuss one or both of these questions:

- **"What's one question still on your mind from lesson one?"**
- **"How does the concept of young carers having a voice in research resonate with you?"**



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# Chapter 1: The Impact of Caring

## Objectives:

- To deepen your understanding of young carers' lived experiences.
- To foster empathy and highlight the importance of identification and support.

# The Impact of Caring – Young Carers Voices



We will be watching a short video featuring the experiences of a young carer. As we watch, consider:



- What challenges did they face?
- How did their caring role impact their life?
- What resonated with you most from the video?
- How does this video enhance your understanding of young carers?

# The Impact of Caring – Understanding a Young Carer's Experience



You will be given a short case study describing a young carer's situation.

In your groups, discuss the following:

- What signs point to this individual being a young carer?
- What potential challenges might they be facing?
- How could you approach this young person sensitively?
- What types of support could be helpful for them?

# Chapter 2: Identifying Young Carers



## Objectives:

- To develop your ability to recognise signs indicating a young person is a carer.
- To provide you with the tools for identifying young carers in various settings.



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## Part 1: Signs and Indicators



"Identifying young carers is crucial for providing early support. It's important to remember that no single sign guarantees that a child is a carer. Think of these as clues to help you better understand their situation."



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# Behavioural Indicators

## Changes in Behaviour

- Frequent absences, lateness, or leaving school early.
- Appearing tired, distracted, or having difficulty concentrating.
- Reluctance to participate in extracurricular activities or socialise with peers.
- Taking on a "parental" role with siblings or peers.



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# Emotional Indicators



## Emotional Signs:

- Seeming anxious, worried, or stressed.
- Changes in mood or expressing feelings of isolation.
- Signs of low self-esteem or feeling overwhelmed.
- Difficulty in managing emotions, irritability, or withdrawal.



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# Situational Indicators



## Clues from their Home Life:

- Mentioning a family member with an illness, disability, or mental health challenge.
- Talking about responsibilities at home that seem beyond their age.
- Limited free time or lack of typical age-appropriate leisure activities.
- Difficulty accessing support.



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# Part 2: Expanded Case Study

Let us look again at Sarah's case.

*Remember, Sarah is a fifteen-year-old student in her final year of secondary school. She lives with her mother, who has multiple sclerosis and experiences fatigue, mobility issues, and occasional flare-ups requiring additional support. Sarah also has a younger brother, Ben, who is ten years old.*

Pinpoint the specific indicators of a caring role.



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# Part 2: Role Play Activity

Scenario 1	Scenario 2	Scenario 3
Caring for a family member.	School and home conflict.	Asking for help.

"We'll work in small groups. Each group will get a scenario. Practice acting it out and observe what signs of caring roles you notice."



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# Chapter 3: Next Steps and Support

## A Professional Development Focus



### Objectives:

- To understand existing support structures within your organisation for identifying and supporting young carers.
- To be able to identify external resources and referral pathways for young carers and their families.
- To develop strategies to empower young carers and promote self-identification.
- To create an action plan to improve young carer support within their professional practice.



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# Activity 1: Support Systems Mapping

**NEXT  
STEPS**

**In your groups, map out:**

- Current processes for identifying young carers within their role.
- Existing support mechanisms they can offer.
- Gaps or barriers in the current system.



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# Activity 2: Empowering Young Carers: Building a Resource Guide



**Your task: Research and compile resources for young carers in your region**

**Group 1: Websites & Helplines**

**Group 2: Community Support Groups**

**Group 3: Educational Materials for Families**



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# Activity 3 From Awareness to Action.

## Your Young Carer Support Plan.

**"Reflect on what you've learned today. Now, let's turn it into practical steps for positive change within your work."**



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# Quiz Question 1:

Which of the following is a common responsibility of a young carer?

- A. Managing the family finances
- B. Providing emotional support to a family member
- C. Driving siblings to school
- D. All of the above



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## Quiz Question 2:

Young carers may experience negative impacts in which of the following areas?

- A. School performance
- B. Mental health
- C. Social relationships
- D. All of the above



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## Quiz Question 3:

A young person is most likely to be considered a young carer if they provide care for someone who:

- A. Has a short-term illness
- B. Is elderly and frail
- C. Has a disability or long-term health condition
- D. Needs help with occasional chores



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# Quiz Question 4:

As a social care worker, an important step in supporting a young carer is to:

- A. Assess their caring responsibilities and the impact on their wellbeing
- B. Take over some of the care duties to reduce their burden
- C. Encourage the young carer to focus exclusively on their schoolwork
- D. Advise the young carer to seek counselling



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# Quiz Question 5:

A key resource you can refer young carers to is:

- A. A local young carers support group
- B. A financial advice service
- C. A job-seeking agency
- D. A driving school



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# Quiz Answers

1) **D**

2) **D**

3) **C**

4) **A**

5) **A**



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# Plenary and Farwell

## Supporting Young Carers: What We've Learned



### Key Takeaways

- Young carers often have hidden responsibilities that impact their lives.
- Proactive identification is crucial – look for subtle signs as well as obvious indicators.
- Sensitive communication builds trust and empowers young carers to self-advocate.
- Young carers benefit most from tailored resources, not a one-size-fits-all approach.
- Every professional can contribute to better support through advocacy and collaboration.



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# Welcome Back!



Our previous session focused on understanding young carers and participatory research.

Now, we'll shift our attention to practical action. In today's lesson, we'll cover how to confidently identify young carers in various settings, strategies for approaching young carers with sensitivity and respect and engaging young carers in participatory research for meaningful impact.

By the end of this lesson, you'll have tools to better recognise, support, and empower young carers in your professional work.



# Recap and Reflection

## KNOWLEDGE CHECK QUIZ



### Objectives:

- To revisit key concepts from Lesson 1.
- To connect previous learning to the current lesson's focus.

We will now take a short quiz to recap what we learned from the previous lesson. Please take your time and remember that this is not a test.

Once you have finished answering the quiz questions, we will review the answers and flag up any further questions that may arise.



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# Recap and Reflection

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# Chapter 2: Identifying Young Carers



## Objectives:

- To develop your ability to recognise signs indicating a young person is a carer.
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# Part 1: Signs and Indicators



"Identifying young carers is crucial for providing early support. It's important to remember that no single sign guarantees that a child is a carer. Think of these as clues to help you better understand their situation."



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## Part 2: Expanded Case Study

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# Chapter 3: Next Steps and Support

## A Professional Development Focus



### Objectives:

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- To be able to identify external resources and referral pathways for young carers and their families.
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STEPS**

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**NEXUS**

# Activity 2: Empowering Young Carers: Building a Resource Guide



**Your task: Research and compile resources for young carers in your region**

**Group 1: Websites & Helplines**

**Group 2: Community Support Groups**

**Group 3: Educational Materials for Families**



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# Activity 3 From Awareness to Action.

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# Quiz Question 4:

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# Quiz Question 5:

A key resource you can refer young carers to is:

- A. A local young carers support group
- B. A financial advice service
- C. A job-seeking agency
- D. A driving school



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# Quiz Answers

1) **D**

2) **D**

3) **C**

4) **A**

5) **A**



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**NEXUS**

# Plenary and Farwell

## Supporting Young Carers: What We've Learned



### Key Takeaways

- Young carers often have hidden responsibilities that impact their lives.
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- Sensitive communication builds trust and empowers young carers to self-advocate.
- Young carers benefit most from tailored resources, not a one-size-fits-all approach.
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# Thank YOU



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**NEXUS**



## Module 1: YOUNG CARERS AND PARTICIPATORY RESEARCH



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### Lesson 4 - Workshop: Simulation of a Recruitment Drive

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# WELCOME BACK, EVERYONE!



Today, we're taking the participatory research skills we've learned to the next level: it's about connecting with young carers and inviting them to participate in your research.

Let's review our objectives for this workshop.



# Workshop Objectives

## Finding the Right Participants: Recruitment Strategies for Young Carers Research



By the end of the workshop

- 1. Understanding Target Audience:** You can define the ideal participant profile for a young carers research project and identify factors influencing inclusion.
- 2. Outreach Strategies:** You will brainstorm diverse outreach channels suitable for reaching young carers, considering access barriers and preferences.
- 3. Crafting Persuasive Messages:** You will develop engaging recruitment messages that resonate with young carers and highlight the value of participation.
- 4. Application:** You will create a recruitment plan for a hypothetical participatory research project, showcasing their understanding of the concepts covered.



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# Activity 1: Project Overview

## Example Research Project with Young Carers

### A process template:

Question: [A focused question about young carers' experiences]

Method(s): [Example: Interviews, focus groups, creative activities]

Goal: [How findings could improve support for young carers]



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# Research Project with Young Carers

## Example 1: Experience-Focused

Question: How does being a young carer impact relationships with friends and peers?

Method(s): Interviews, focus groups, creative expression (art, journaling)

Goal: Understand the social challenges and support needs of young carers from their own perspectives.

Your task is to consider how to recruit young carers who would be a good fit for this kind of study.



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# Research Project with Young Carers

## Example 2: Support Systems

Question: What makes young carers feel supported or unsupported by their schools?

Method(s): Interviews, youth-led surveys within schools

Goal: Gather young carers' ideas for making schools more responsive to their unique needs.

Your task is to consider how to recruit young carers who would be a good fit for this kind of study.



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# Research Project with Young Carers

## Example 3: Policy Impact

Question: What barriers do young carers face in accessing [specify a type of service: respite care, counselling, financial aid]?

Method(s): Interviews, photovoice project to document challenges

Goal: Use findings to advocate for policy changes that improve service accessibility for young carers.

Your task is to consider how to recruit young carers who would be a good fit for this kind of study.

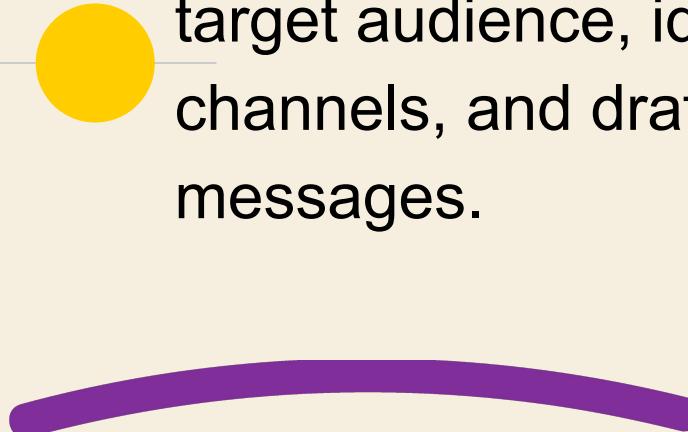


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# Activity 2: Small Group Planning



**Objective:** In your groups, design inclusive recruitment strategies for the research project, including defining the target audience, identifying outreach channels, and drafting persuasive messages.



## Activity 2: Key Points

Think Inclusivity: "How can we reach ALL young carers who might be interested?"



Project Reminder: Briefly display the project question from the “Example Research Project”

Target Audience Considerations:

Age range?

Types of caring roles?

Where do they spend time?

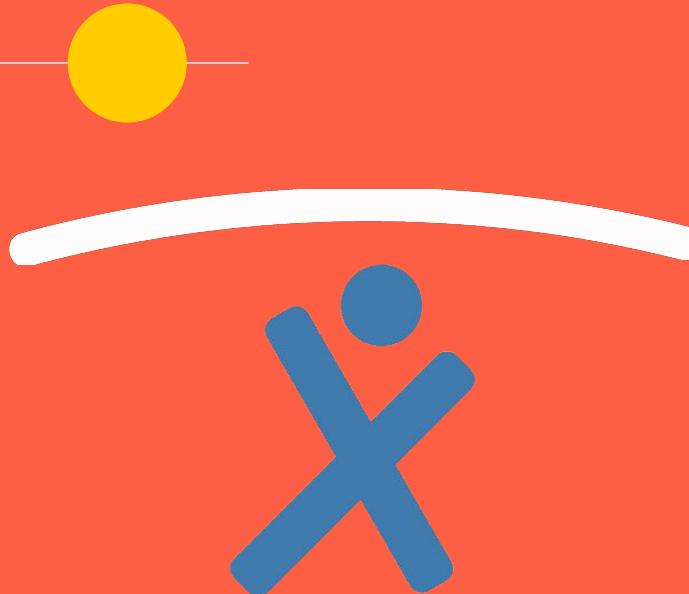


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## Activity 3: Presentations & Feedback

**Objective:** Each group presents its recruitment plan, followed by feedback discussions



# Activity 4: Reflection



**Objective:** Discuss challenges and opportunities encountered during the simulation and connect learnings to your real-world practice.



# Reaching Young Carers: Lessons Learned



"Young carers are not just subjects of research,  
they are experts in their own lives.  
Their active participation is vital to creating  
meaningful change."



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# Thank YOU



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# Module 1

## Young Carers and Participatory Research



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### Lesson 3: Designing Participatory Research with Young Carers

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# WELCOME BACK, EVERYONE!

In our previous sessions, we explored the lived experiences of young carers and the importance of participatory research.

Today, we'll take that to the next level by learning how to design research projects that put young carers at the center."



# Lesson Objectives

- **By the end of the lesson, you will be able to:**
- **Fundamentals:**
  - To outline the key stages in designing a research project.
  - To define a research question focused on the needs and experiences of young carers.
- **Participatory Methods:**
  - To identify and describe participatory research methods appropriate for working with young carers.
  - To brainstorm how to adapt research methods to be inclusive and empowering for young participants.
- **Collaboration:**
  - To understand the principles of co-design in research projects with young carers.
  - To discuss strategies for facilitating young carers' meaningful contributions throughout the research process.



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# Designing Participatory Research With Young Carers.



Let's begin...



# Research Roadmap

## The Stages of a Research Project



Defining the Question > Choosing Methods > Data Collection > Analysis > Sharing Findings



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# It starts with a question...



**Focused on the lived experiences of young carers**

**Clear and researchable (not too broad, not too narrow)**

**Relevant to practice or policy change**



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# Finding the Questions that Matter



***Key point: Young carers' voices are essential in identifying what to research***

## Brainstorming Prompts:

- **Challenges:** What are the biggest difficulties young carers face that need further exploration?
- **Positive Impacts:** Are there less-discussed ways caring might benefit young people? How can research illuminate this?
- **Gaps in Knowledge:** What do we NOT know enough about regarding young carers' lives?
- **Asking Young Carers:** If you could ask young carers themselves, "What should we research about your experiences?" what would they say?



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# Beyond Traditional Methods

## Engaging Young Carers as Researchers

***Key point:***  
***Participatory research  
unlocks the best insights  
from young carers***

- Interviews (individual or focus groups)
- Creative expression (art, journaling, drama)
- Photovoice
- Youth-led surveys



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**NEXUS**

# Method 1: INTERVIEWS

**One-on-one or small group conversations guided by open-ended questions**

- **Empowering**
- They give young carers space to share their experiences in their own words.
- They allow for building rapport and exploring complex issues in depth.
- **Challenges**
- Requires good listening and facilitation skills on the researcher's part.

Ensuring a comfortable setting for the young carer is crucial.



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**NEXUS**

# Method 2: CREATIVE EXPRESSION

**Using arts-based activities (drawing, writing, drama, etc.) for young carers to express their experiences and perspectives**

- **Empowering:**

- Offers an alternative form of communication, especially valuable for those less comfortable with verbal sharing.
- It can reveal insights that might not emerge in a traditional interview.

- **Challenges:**

- Requires researchers to have some facilitation skills in creative methods.
- Interpretation needs to be done sensitively, in collaboration with the young artists.



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# Method 3: PHOTVOICE

**Young carers take photos representing their experiences, then discuss their meaning in individual or group settings**

- **Empowering:**

- Puts control in young people's hands – they decide what aspects of their lives are important to document.
- Photos can be a powerful tool for advocacy and raising awareness.

- **Challenges:**

- Ensuring ethical use of photographs, especially if shared publicly.
- Requires time for photo-taking and thoughtful discussion afterwards.



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# Method 4: YOUTH-LED SURVEYS

**Young carers design and distribute surveys to their peers, gathering data on a larger scale.**

- **Empowering:**

- Positions young people as experts, deciding what questions are important to ask.
- Can reach a wider group of young carers efficiently.

- **Challenges:**

- Requires some guidance on survey design for accurate results.
- May need adult allies to help with distribution and data analysis



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# More Than Participants.

## Co-Researchers: Building Partnership with Young Carers



***Key point: Young carers' expertise enhances our research and its real-world impact***

- How can we involve them in shaping the question?
- What role can they play in data analysis and making sense of the findings?
- How do we share results in ways that empower young carers rather than just studying them?



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# Benefits of Collaboration.

## Why Partnership Matters



***Key point: Collaboration with young carers leads to better, more impactful research.***

- Gaining deeper, more nuanced insights
- Designing research that is relevant and addresses real needs
- Ensuring ethical practice, putting young carers' well-being first
- Results more likely to lead to positive change



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### Key Takeaways

- Well-designed research can be a tool for improving young carers' lives
- Participatory methods unlock young carers' unique perspectives
- True collaboration with young carers at every stage is essential





# Thank YOU



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**NEXUS**