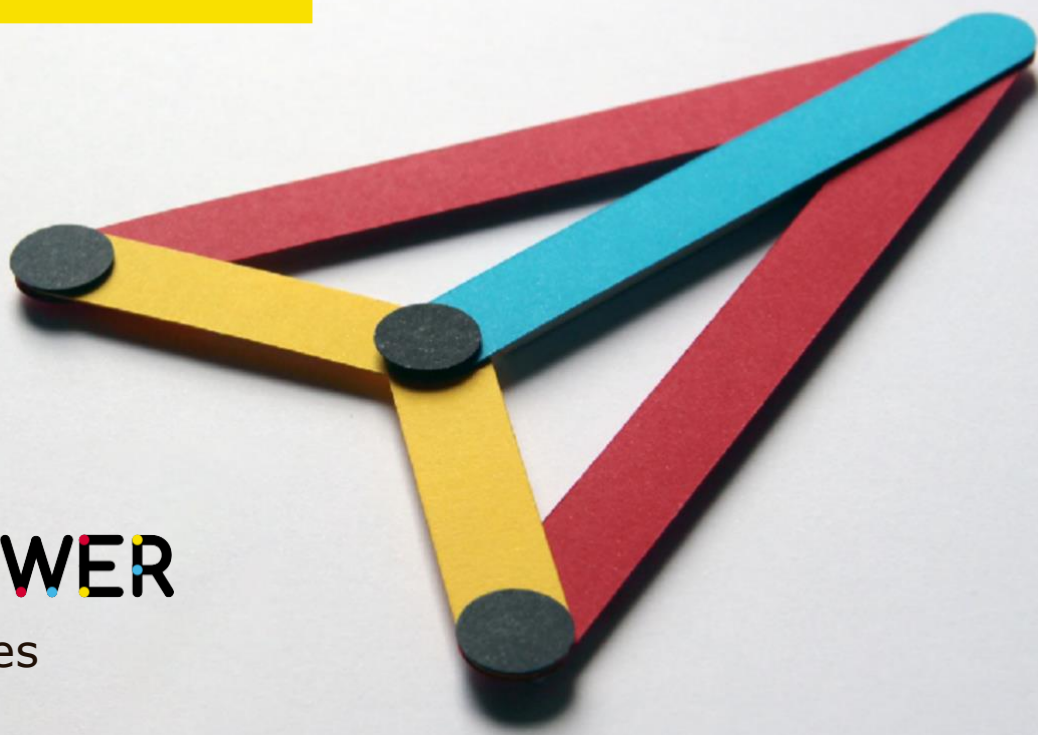


D5.4

EMPOWER

deliverables



Deliverable name

Lessons learned

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R - Document Report

Dissemination level

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Date



In this report, Work Package 5 presents findings from the semi-structured interviews they conducted over the past nine months with EMPOWER partners and Work Package 5's final ethical reflections and recommendations.

Description

WP.5

Work Package. 5

RU

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1. Introduction

In this report, Work Package 5 presents findings from the semi-structured interviews they conducted over nine months with EMPOWER partners and Work Package 5's final ethical reflections and recommendations. The first half of the report deals with the former topic, while the second half deals with the latter.

As explained in deliverable 5.3, Work Package 5 began interviewing EMPOWER partners in early 2025 to translate their stated experiences into recommendations for other projects with comparable goals and structures to EMPOWER. Work Package 5 has since completed 8 more interviews and used them to develop the recommendations outlined in the first half of this report. As we already detailed our methods and intentions in deliverable 5.3, we encourage readers who wish to learn more about how and why we conducted these interviews to consult this document. In the second half of this report, we provide ethical reflections and recommendations based on our own experiences working with EMPOWER (rather than the partners we interviewed). We will explain why we decided to do this in further detail shortly.

2. Challenges and recommendations

2.1. INTERVIEW RESULTS

In deliverable 5.3, we introduced 8 coding themes we used to interpret the interviews we conducted with EMPOWER partners in 2025. These themes were subdivided into “challenges” and “recommendations”.

We have used this coding scheme to interpret 8 additional interviews. As such, our readers should consider the following results section to represent the continuation of the research we presented in deliverable 5.3. Indeed, we highly recommend that our readers review deliverable 5.3 before reading deliverable 5.4 as we will refer to its content throughout this document.

2.2. CHALLENGES: ABRUPT BEGINNING AND CONCLUSION

In deliverable 5.3, we highlighted that many interview participants wished that EMPOWER continued for at least one more year.

They explained that this would have provided them with more time to learn how to successfully collaborate and ensure they could adequately exploit EMPOWER's results. Most of the 8 additional interview participants expressed similar concerns. They also provided several recommendations that we did not cover in deliverable 5.3.

2.3. RECOMMENDATIONS: ABRUPT BEGINNING AND CONCLUSION

Several participants suggested that EMPOWER would have benefited from establishing additional means to ensure that its technically oriented members could share data and code right from the beginning. For instance, one mentioned that they would have appreciated it if EMPOWER had a shared, well-documented GitHub right from the project's start.

Both participants suggested that this would have helped them collaborate more effectively with their colleagues, especially during the early phases of the project. Several participants also mentioned that projects like EMPOWER should aim to define the scientific measures all their partners will use in their work as early as possible (e.g., in their proposals) to facilitate translation and operationalization efforts.

The participants also highlighted that they would have appreciated it if they had more time to reflect on their progress and workflows after milestones such as the pilot studies. They explained that they wished that EMPOWER (and EU-funded projects of its kind in general) treated these milestones more like learning moments than end goals. Indeed, many mentioned that they learnt a lot while preparing for, executing, and completing the milestones, but felt they did not have sufficient time to properly incorporate such knowledge into their research before they had to focus on another deadline.

As such, they highly recommended that other projects treat milestones as test beds for research already completed and provide partners with time to reflect on what works and what doesn't after their completion.

2.4. CHALLENGE: INTERDISCIPLINARY COMMUNICATION

Much like the previous cohort, the additional interview participants emphasized that collaborating with researchers from other disciplines can be challenging.

Many, particularly those in technical roles, reported frequently taking on tasks beyond their formal responsibilities because no one else had the necessary expertise. They attributed this to disciplinary biases. Colleagues from other fields, they explained, often underestimated the time and effort involved, assuming the tasks were simpler than they actually were.

While participants understood that such situations were largely unavoidable given EMPOWER's work package structure, and were generally willing to step in, they expressed a desire for clearer role definitions to better anticipate the scope of their responsibilities.

2.5. RECOMMENDATION: INTERDISCIPLINARY COMMUNICATION

Several participants who had taken on tasks beyond their formal responsibilities recommended that projects like EMPOWER include an additional work package to more effectively distribute labor.

One participant noted that EMPOWER would have benefited from both hiring more developers and dedicating an entire work package to development.

Others proposed similar solutions, echoing a common sentiment: while they were generally willing to take on extra work, they wished their colleagues would better understand how labor-intensive those tasks could be.

Having a senior partner from the proposed development work package present at 100% meetings involving technical decisions, they suggested, could help mitigate this issue by ensuring that someone with the necessary expertise is available to accurately assess the time, effort, and resources required for development tasks—and to advocate for more realistic expectations during planning.

2.6. CHALLENGE: RECRUITMENT AND ROLES

During this round of interviews, participants primarily referred to Work Package 5 when discussing recruitment and roles.

While they appreciated Work Package 5's contributions to EMPOWER, many felt it could have been more fully integrated into the project as a whole.

Several also noted that, beyond the formal ethical requirements of their respective disciplines, they had limited knowledge of ethics and wished that Work Package 5 had offered more opportunities to learn, particularly in relation to artificial intelligence and disability. In fact, multiple participants suggested that ethics should, and likely will, play a more central role in future projects like EMPOWER, especially in light of recent EU AI regulations. As such, they argued, both researchers and funding bodies should prioritize fully incorporating ethics work packages into interdisciplinary projects from the get-go.

2.7. RECOMMENDATION: RECRUITMENT ROLES

The additional participants, much like the previous cohort, expressed that Work Package 5 could have contributed more to EMPOWER by developing practical tools and strategies to support other work packages in addressing ethical concerns on a day-to-day basis.

For instance, several participants emphasized the importance of the ethics work package liaising more closely with other teams to ensure that all partners share a common understanding of ethical requirements—particularly those that vary across national contexts.

Non-EU countries, for example, often have different data protection and research ethics standards than EU member states. Some participants also noted that their academic disciplines did not require them to engage deeply with ethics training, despite recognizing its importance in projects like EMPOWER, which involve vulnerable populations.

As such, they suggested that ethics-focused work packages develop discipline-specific workshops. Examples included a session on data ethics and disability tailored for computer scientists, and another on participatory research design and disability aimed at empirically-oriented researchers.

2.8. CHALLENGE: PARTICIPATORY RESEARCH DESIGN

Two of the eight participants explicitly discussed participatory research design during their interview.

The first noted that gathering data from parents was harder than they expected and explained that other projects working with neurodiverse children should prioritize doing so because parents know their children better than anyone.

While the second reported that EMPOWER could have benefited from recruiting sensitivity readers to ensure that its documentation is inclusive, responsible, and respectful. Both challenges have relatively straightforward solutions.

2.9. RECOMMENDATION: PARTICIPATORY RESEARCH DESIGN

Regarding the recruitment of parents, the participant suggested that other projects should conduct focus group sessions with them that center around gathering data concerning their knowledge of their children's interests, capabilities, and personalities.

It is worth noting here that EMPOWER did conduct focus group sessions with teachers and experts that proved to be exceptionally useful. On the topic of sensitivity readers, the participant in question recommended that the ethics work packages lead such efforts and recruit neurodiverse individuals with media training to serve as sensitivity readers.

These sensitivity readers should review all documentation that may influence how people interact with neurodiverse children or how these children engage with the technology being developed. The participant stressed that failing to do so risks unintentionally harming children due to a lack of awareness or understanding.

3. Final ethics recommendations

In this section, Work Package 5 presents its final ethical recommendations based on our experiences working with EMPOWER.

These recommendations are intended for researchers involved in the development of assistive technologies for the neurodiverse community, as well as for decision-makers responsible for funding or overseeing such projects.

As we have outlined our intentions and methods in more detail elsewhere (e.g., in Deliverables 5.1 and 5.2), we will only briefly touch upon the processes followed to develop these recommendations here. To briefly reiterate, these recommendations were developed by synthesizing insights from the ethical literature, our experiences as ethics consultants working with EMPOWER, and feedback from other project partners.

We should also emphasize that, although partly inspired by the interviews we conducted with EMPOWER members, the following recommendations are our own and represent Work Package 5's expert opinions.

3.1. ON-THE-GROUND ETHICS FEEDBACK (NOT MONITORING)

While working with EMPOWER, it became clear that the project would have benefited from hiring a junior ethics specialist from the outset who could collaborate with other partners on a day-to-day basis.

Due to time constraints mentioned elsewhere, this did not happen right from the project start. Ideally, this staff member would have expert knowledge of disability studies, experimental ethics, science and technology studies, and the neurodiversity rights movement, and provide other partners with ethical guidance whenever necessary.

Knowing when such guidance is necessary, however, can be tricky. As such, we recommend that this junior ethics specialist attend all inter-work package meetings and hold regular office hours (e.g., weekly or biweekly) that focus on helping other partners integrate insights from the disciplines above into their workflows and research design.

It is important to stress that this role should be specialized (e.g., focused specifically on disability, autism, and ADHD) rather than ethics in general. We raise this point because EU-funded AI projects

often include ethics work packages but seldom require them to specialize in the way we are proposing.

Given that EMPOWER (and similar projects) work with vulnerable populations, we strongly recommend hiring ethics specialists with demonstrable experience working with such groups.

We should emphasise that this junior ethics specialist's role would be to facilitate ethical reflection and help establish relevant practices, such as formal and informal studies that align with participatory research goals, rather than to monitor other partners' workflows. Their primary responsibility would be to use their knowledge and experience to support partners, particularly during moments of uncertainty around how to ethically integrate insights from vulnerable groups into their research. This might include, for example, the design of studies involving human participants or the processing of sensitive data. In short, the junior ethics specialist should be the go-to person for ethics-related guidance, functioning more like a consultant or technician who enables others to make well-informed ethical decisions, rather than an authority who unilaterally determines what is best for the project or the community it seeks to support.

3.2. BROADENING ETHICS WORK PACKAGE RESPONSIBILITIES AND MEMBERSHIP

EMPOWER's WP5 included only two partners: Pim Haselager and Thomasin Coggins. However, ethical considerations were addressed by all Work Packages, often without direct input from WP5. This was particularly evident in tasks such as developing study protocols, applying for approval to study human participants through university ethics boards, and gathering feedback from the neurodiverse community.

WP5's limited involvement in these matters was likely because many partners were already well-versed in handling these responsibilities in accordance with national legal and ethical standards, and therefore did not feel the need to seek additional consultation. While this approach ensured compliance, it may have placed additional, and arguably avoidable, strain on partners whose primary focus was not ethics.

As such, we recommend broadening ethics work packages' responsibilities and membership to ensure tighter collaboration between partners when it comes to ethics and decrease the labor non-ethical work packages expend on ethics.

The previous recommendation (3.1) would partly deal with this matter by ensuring that all partners are aware they can approach and will regularly hear from an ethics specialist, ideally with expertise in experimental ethics.

We also propose that at least one partner from each non-ethics Work Packages be officially allocated time and responsibilities related to ethics—potentially by serving as a partial member of the ethics WP. In EMPOWER, an “ethical reflection team” was established roughly a third of the way through the project with this intention, and it proved exceptionally useful.

However, in practice, the team primarily advised WP5 on the feasibility of its ethical recommendations, rather than seeking guidance from WP5 on emerging ethical issues within their own WPs. For future projects, we recommend placing greater emphasis on fostering ongoing dialogue between ethics and non-ethics Work Packages.

One effective approach could be to ensure that representatives from non-ethics WPs meet with ethics specialists whenever ethically relevant issues arise, especially during key phases such as the planning of studies involving human participants. This would promote a more proactive and integrated approach to ethical oversight, while also distributing the responsibility more evenly across the consortium.

3.3. PARTICIPATORY RESEARCH DESIGN

As suggested throughout the second half of this report, we strongly recommend that ethics work packages play a more active role in the day-to-day workflows of projects like EMPOWER. In particular, we believe they should focus on helping other partners incorporate knowledge from end-users and stakeholders into the project’s research design.

Although WP5 did provide recommendations in this regard (see deliverables 5.1 and 5.2), we believe we could have enriched EMPOWER’s research by either leading or contributing to projects that center around this goal. For instance, many partners mentioned during our interviews with them that EMPOWER would have benefited from receiving more input from various stakeholders, most notably, research participants’ parents and neurodiverse adults.

We have several suggestions for other projects in this regard. First and foremost, we encourage them to lean more heavily on their ethics work packages when developing strategies to gather knowledge from stakeholders.

For example, projects could include a specific deliverable or milestone within the ethics work package that documents what participatory research design practices were—or will be—used (see

recommendation 3.4). This approach not only highlights the importance of stakeholder involvement but also helps motivate all relevant partners to engage meaningfully with these practices throughout the project.

Indeed, we generally encourage other projects to ensure their ethics work packages are more involved in the day-to-day implementation of participatory research design. This could include providing ethics teams with additional responsibilities, such as recruiting sensitivity readers, (co)coordinating focus groups, or assisting other work packages in fulfilling obligations related to participatory research design when needed. Ethics work packages would not necessarily be obliged to lead these activities. Instead, they should be involved in them and, ideally, help other partners, many of whom may already know how to conduct such studies, design and execute them by reviewing documentation, liaising with team members and external parties, and providing ethical guidance when needed.

Additionally, the partners we interviewed often mentioned that they would have appreciated if work package 5 had provided them with educational resources regarding participatory research design and the ethics of technology. Indeed, many expressed a desire to expand their understanding of ethics, particularly as it relates to their academic disciplines, but did not know where to begin. As such, we recommend that ethical work packages offer educational services (e.g., introductory workshops) to other partners to familiarize them with the foundational principles of participatory research design as they apply across different disciplinary contexts. Such efforts would count as one of the “strategies used to integrate knowledge from vulnerable groups” discussed in the following recommendation (e.g., could be reported upon in relevant deliverables).

3.4. ETHICAL FRAMEWORKS AND DELIVERABLES

EMPOWER’s proposal specified that WP5 would develop an ethical framework to guide the project’s ethical decision-making. This framework was completed around the midpoint of the project and presented in Deliverables 5.1 and 5.2. Many partners we spoke to—both during interviews and informal conversations—expressed appreciation for the recommendations provided by the framework. However, they also noted that its development and implementation could have been improved. WP5 shared similar reflections internally and concluded that it might

have been more effective to reverse the process we followed—by first focusing on providing practical, on-the-ground ethical guidance at the beginning of the project, and then later using those experiences to develop a framework that could benefit future initiatives.

Allow us to explain why. Although both Deliverables 5.1 and 5.2 proved to contain valuable insights, they were completed after many of our colleagues had already designed, set up, and in some cases completed studies that might have benefited from our ethical input earlier in their research design and execution. As such, we believe that ethics work packages in projects like EMPOWER should prioritize developing practical mechanisms to foster dialogue and engagement with other partners at the outset, rather than focusing initially on creating a formal ethical framework from scratch, as we did. Indeed, ethical work packages' first few deliverables could focus on documenting how this early engagement was carried out, using qualitative methods similar to those employed in Deliverables 5.3 and 5.4 (e.g., interview summaries, field note write-ups, or brief ethnographic reports).

These insights, grounded in the lived experiences of researchers and participants, could then serve as a foundation for more robust ethical guidance. Building on this, ethical work packages could later draw on these findings, along with their disciplinary expertise and hands-on experience within the project, to develop recommendations that external researchers can use and build upon when designing technologies for neurodiverse individuals and, potentially, other vulnerable groups. With this in mind, we recommend that other projects have their ethics work packages' create deliverables that focus on the following topics:

Deliverable 1: a report on the formal and informal strategies that have already been or will be used to integrate knowledge from vulnerable groups into the project's research design.

Deliverable 2: a report on the "lessons learnt" from the strategies mentioned above. For instance, what strategies were successful, need improvement, or ultimately proved unfeasible given the limitations of a project. This report also outlines how the ethics work package, and the project in general, intends to use these lessons learnt moving forward.

Deliverable 3: a report on the additional formal and informal strategies used to integrate knowledge from vulnerable groups into the project's research design, outlined in deliverable 2.

Deliverable 4: a final reflection on the challenges, accomplishments, and overall value of the ethical strategies used by the project that the ethics work packages translate into actionable recommendations directed towards other researchers and, ideally, policy-makers.

As suggested earlier, we strongly believe that ethics work packages should primarily focus on helping other partners develop ways to integrate knowledge from vulnerable groups into their research design and daily workflows. Accordingly, projects like EMPOWER should motivate their ethics work packages to establish and document strategies aimed at advancing this goal through relevant deliverables.

4. Conclusion

In this report, we presented the results of the interviews conducted with EMPOWER partners, along with our concluding ethical recommendations based on our experiences working on the project.

We hope that this report, together with the other ethical deliverables developed over the past three years, will assist future projects like EMPOWER in developing technologies for the neurodiverse community effectively and responsibly.

As stated in Deliverable 5.3, we will continue the research presented here and in previous deliverables by developing a research paper that further elaborates on the interview results and provides detailed recommendations for researchers working on projects like EMPOWER.