

Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths (DANCING)

Report Qualitative Data Collection and Archiving in the DANCING Project

Delia Ferri, Tiarnán McDonough and Alessia Palladino

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Corresponding Author: Prof. Delia Ferri, School of Law and Criminology/ALL Institute, Maynooth University, Maynooth, Co. Kildare, Republic of Ireland (<u>Delia.Ferri@mu.ie</u>).

Orcid: orcid.org/0000-0002-8193-5881

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EXECUTIVE SUMMARY

This report presents an overview of the qualitative data collection and archiving carried out in the European Research Council (ERC) funded project '*Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths – DANCING*'.

DANCING comprises four different work packages (WP). Three of them are related to the key objectives of the project (experiential, normative and theoretical), while the fourth focuses on translating the research into practical tools that can effect societal change. DANCING adopts a socio-legal perspective, i.e. pursues an analysis of law that is directly linked to the analysis of the social situation to which the law applies. Consistent with this perspective, in order to achieve the three objectives indicated above, it combines legal doctrinal research, qualitative research and arts-based research. Qualitative research was employed within WP1 and WP2, and it involved mainly semi-structured interviews and focus groups. Specifically, a range of interviews were conducted with different cohorts of national and European stakeholders. In order to accommodate different needs, in some instances, qualitative questionnaires were used as an alternative to interviews.

Within the remit of WP1, data were collected through 41 interviews and 23 written questionnaires with representatives of national organisations of persons with disabilities (OPDs), national organisations of Deaf people, and national organisations that work on disability and art. In addition, in WP1, 10 interviews were conducted with representatives of umbrella organisations of cultural producers, artists, and cultural industries active at the European level. Data gathered from these interviews were complemented by two focus groups, whose participants were mainly people working on access and disability issues in the cultural and creative sectors in different European Union (EU) Member States (e.g. working in galleries, museums or libraries...) or working within European projects to facilitate or promote greater access for people with disabilities. The focus groups discussed barriers to accessing and producing culture, in that way complementing data collected through interviews and questionnaires. The focus groups took place on two separate days, in December 2021. There were nine participants in one group, from five European countries, and 11 participants in the other drawn from eight countries.

Qualitative research in WP2 comprised three sets of qualitative interviews. Ten interviews were specifically designed, deployed and conducted with representatives from umbrella nongovernmental organisations (NGOs) working on disability issues at the EU level and OPDs. There were also 10 participants drawn from 'policymakers' (broadly conceived of), including staff at the European Commission, the European Parliament and other bodies within the EU whose work either centres on or concerns the rights of persons with disabilities (with nine participating in interviews, one completing a questionnaire). Another set of 10 interviews was carried out with a range of different stakeholders and policy makers dealing with cultural cooperation and disability within EU external relations. Qualitative data collected across WPs 1 and 2 comprised a total of 80 interviews and 24 written questionnaires, as well as two focus groups. All participants were aged over 18 years and participated as volunteers in the research. The interviews were, for the most part, conducted in English, with all reasonable accommodations necessary.

On the whole, 64 interviews and two focus groups were archived with the consent of the participants. Since in many cases questionnaires gave a considerable amount of information about the participant organisation's work and this was often by way of naming other organisations or describing the work of other organisations (and often providing website links), ultimately, the decision was made to not archive questionnaires as that would have required, in most cases, to delete a considerable amount of the data to ensure anonymity. The process of archiving data included various steps, in compliance with the DANCING Data Management Plan (DMP) (Ferri, 2021) and in alignment with best practices as outlined *inter alia* by Gray et al. (2011). The key goal of archiving data is to facilitate re-use of data collected by DANCING in the long term.

The main steps in the preparation of data for archiving were: the development of a bespoke anonymisation plan to preserve respondents' privacy and confidentiality as required under the consent agreement; and an extensive data-anonymisation process. In compliance with best practices, data-anonymisation entailed the elimination of all participants' personal information as well as information that could disclose the identity of participants. Further, in some instances, it was deemed appropriate also to eliminate information on third parties mentioned from within participants' social groups, families or workplaces. The anonymisation process was carried out taking into account the main purpose of the qualitative research as well as research questions at the core of the DANCING project. A Quality Assurance (QA) process was also implemented. In fact, while it is relevant for research purposes to gather as much data as possible for both current and potentially future research, it is also necessary to grant the participants' anonymity, given the sensitive and personal information discussed in some cases.

Anonymised data were archived with the Irish Qualitative Data Archive (IQDA), which is a central access point for qualitative social science data generated in Ireland. The IQDA is also a founding member of the Digital Repository of Ireland (DRI) which is a national trusted digital repository for Ireland's social and cultural data, and is available for use by the public, students and scholars.

To comply with requirements for data to be FAIR (Findable, Accessible, Interoperable and Reusable), data were archived together with a set of accompanying files, including contextual documents to describe the overall DANCING project; metadata, that described each transcription of both interviews and focus groups; research instruments (i.e. the topic guide and a template of the consent form). Further, the Depositor Agreement with IQDA was signed and deposited. This agreement allows IQDA to distribute the overall DANCING dataset for use under the Creative Commons Licence CC BY-NC-ND (Attribution-NonCommercial-NoDerivs).

1. INTRODUCTION

This introductory section outlines the DANCING project and its main tenets as well as the primary objectives of the present report and sets out its structure. Moreover, this introduction comprises a note on the terminology used in the project and this report.

1.1. The DANCING Project

The project 'Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths (DANCING)' explores the right of persons with disabilities to take part in cultural life as an essential aspect of enhancing cultural diversity in the European Union (EU). The project is funded by the European Research Council (ERC) and is based at Maynooth University (MU) under Professor Delia Ferri as a Principal Investigator (PI). It explores the extent to which the protection of the right of people with disabilities to take part in culture and the promotion of cultural diversity intersects and complements each other in the EU legal order. It aims to produce ground-breaking knowledge with a view to challenging the cultural exclusion often faced by people with disabilities, and ultimately making European society more inclusive and culturally diverse.

DANCING commenced on 1 September 2020 and is due to be completed on 31 August 2025. It included three main research work packages. Work Package 1 (WP1) aims to identify and categorise barriers to and facilitators of cultural participation experienced by persons with disabilities, and to understand how they affect the wider cultural domain; hence the objective was experiential. Work Package 2 (WP2) endeavours to provide a normative overview of how the EU has used and can use its competences to ensure accessibility of cultural activities and to promote disability identities, while achieving cultural diversity. Work Package 3 (WP3) aims to advance the understanding of the legal concept of cultural diversity. These WPs relate to the key objectives of the project (experiential, normative and theoretical). Notably, DANCING also comprises Work Package 4 (WP4), aimed at translating the academic research into practical tools that can effect societal and policy change.

DANCING adopts a socio-legal perspective, i.e. pursues an analysis of law that is directly linked to the analysis of the social situation to which the law applies. Consistent with this perspective, in order to achieve the three objectives indicated above, it combines legal doctrinal research, qualitative research and arts-based research.

1.2. The Underpinning Tenets of the DANCING Project

DANCING is informed by the principles and rights set out in the CRPD. In particular, DANCING embeds the concept of disability as laid out in Article 1(2) CRPD: this provision recognises that persons with disabilities include those 'who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. DANCING also embraces the

view that 'disability is a social construct' and 'is one of several layers of identity' (CRPD Committee, 2018a).

Consistent with the CRPD terminology, the report uses 'people first language' (i.e. persons/ people with disabilities), and organisation of persons with disabilities (OPDs). In that regard, for the purpose of this research, OPDs are defined in line with the CRPD General Comment No. 7 (CRPD Committee, 2018b).

The project conceives of the right to participate in culture in a comprehensive way, considering both its individual twofold dimension and collective aspect (Romainville, 2015; Chow, 2018). The individual dimension includes both the right to cultural consumption - meaning the right to access cultural activities, goods and services - and the right to active involvement in culture, which includes the engagement in the creation of cultural goods, services and activities. On the other hand, the collective aspect entails the right of cultural communities to be recognised and protected, as well as to enjoy and make use of their cultural heritage and cultural expressions.

1.3. Aim of This Report

This report outlines the main phases and aspects of the qualitative research conducted in the remit of DANCING. In particular, it describes the process for collecting, managing and archiving qualitative data with the Irish Qualitative Data Archive (IQDA). In that regard, this report aligns with ERC's commitment to data archiving as vital step to make data available to the scientific community. As ERC notes, 'data deposition can be complementary to publication, but data can also be deposited without an associated publication' (ERC, 2022).

As will be expounded later, the data collection and archiving has been done in line with the DANCING project's ERC Data Management Plan (DMP) (Ferri, 2021), which lays out the project's data management approach, consistent with the ERC commitment to Open Science, including open access to research publications and FAIR data principles (ERC, 2019).

1.4. Structure of This Report

Following these introductory remarks, this report moves on to outline the general features of qualitative research conducted within the DANCING project. Then it discusses data collection and preparation for data archiving. Particular attention is paid to the process of anonymisation and Quality Assurance (QA). The report moves on to examine the data archiving process.

2. THE QUALITATIVE RESEARCH IN THE DANCING PROJECT

This section presents the main features of the qualitative research carried out within the DANCING project.

2.1. Overview

Qualitative research was conducted within the DANCING project to identify and comprehend barriers experienced by people with disabilities in cultural participation as well as facilitators of such participation, to understand the extent to which lack of accessibility and lack of recognition of disability identities affects the EU cultural domain as a whole, and to understand the role and impact of EU law on cultural rights of persons with disabilities.

Qualitative research was carried out through five sets of interviews (conducted with different groups of interviewees, in connection with WP1 and WP2 of the project) and two focus groups (deployed in WP1).

The semi-structured interview format was purposely chosen, partly because of the organisation of structured interviews but also because it allows the flexibility to ask probing or follow-up questions based on the participant's responses. Thus, this format grants the researcher the possibility to interject with additional questions as deemed appropriate. In line with best practice in qualitative research, a flexible approach was adopted (Foley, 2021; Taylor et al., 2015), which was particularly necessary since this specific research project involved participants using a range of different languages, and requiring reasonable accommodations (such as sign-language interpretation) to facilitate participation in some cases. It must also be noted that the qualitative research was commenced during the COVID-19 pandemic, which ruled out doing face-to-face interviews for the most part. This also meant that the vast majority of interviews and the two focus groups were conducted online. However, as noted by previous research, 'many of the same interpersonal processes and dynamics that characterize face-to-face interactions also characterize online interactions' (Stewart and Shamdasani, 2017).

Further, as an alternative to participating in an interview, qualitative questionnaires were provided, seeking open-ended or free-text answers and enabling participants to respond in writing in English or in a language of their choice, as a reasonable accommodation measure. In some cases, the questionnaires were translated into the participant's local language, completed in that language, and the answers subsequently translated into English. While data gathered by written questionnaire can limit the depth and richness of responses, in this case they allowed for open-ended responses that contributed to an in-depth study of individual cases (Blaxter et al., 2010). Overall, a total of 80 interviews and 24 qualitative questionnaires were conducted.

In order to carry out qualitative research, the project sought ethical approval from the Maynooth University Research Ethics Committee, which was received on 10 December 2020.

2.2. Qualitative Research in WP1

Within the remit of WP1 two sets of interviews and two focus groups were carried out.

2.2.1. Interviews

The first set of interviews aimed to collect data on barriers to access, production and enjoyment of cultural goods and services experienced by people with disabilities across the EU. Further, these interviews were aimed to gain a better understanding of what facilitates cultural participation of persons with disabilities. A topic guide was used to invite the participants to identify the key barriers to participation in culture by people with disabilities in their countries as they perceived it, as well as key facilitators.

All in all, 41 interviews and 23 written questionnaires (as an alternative to interviews) were conducted with representatives of national OPDs, national organisations of Deaf people, and national organisations that work on disability and art¹. Of these, 34 interviewees granted consent for archiving.

The second set of interviews aimed to understand to what extent the lack of accessibility and lack of recognition of disability identities affects the cultural domain as a whole in the EU. Interviewees included representatives from umbrella organisations of cultural producers, artists, and cultural industries active at the European level. A total of 10 interviews were completed².

2.2.2. Focus Groups

The data gathered through interviews was then complemented by data collected in two focus groups. Focus groups were chosen as they allow for the collection of qualitative data through group discussions. In that regard, they use participants' discussions to produce data that would be less accessible without that interaction (Morgan, 2019; Acoccella and Cataldi, 2021). The strengths of the focus group as a research method, therefore, come from the insights that arise during interaction among the participants, with this dynamic considered especially valuable because it can show the extent of consensus and diversity within the group and provide information about the sources of those similarities and differences (Morgan, 2019).

The choice of conducting focus groups online was dictated not only by the ongoing pandemic (at that time), but also underpinned by the need to facilitate participation from various European countries. However, scholarly work has evidenced that focus groups by video are comparable to face-to-face groups, with Gothberg et al. (2013), for example, reporting equivalent breadth in terms of the range of topics discussed.

¹ These interviews are identified as the first dataset in Table 4.

² These interviews are identified as the second dataset in Table 4.

The aim of the focus groups was that of discussing barriers and facilitators to cultural participation of persons with disabilities, in that way complementing data gathered through interviews. Participants were people working on accessibility in arts organisations or institutions as well as in European projects on arts and disability.

The focus groups took place on two separate days, in December 2021. There were nine participants in one group, from five European countries, while 11 people, drawn from eight countries, partook in the other.

2.3. Qualitative Research in WP2

Within the remit of WP2, three sets of interviews were carried out. As outlined above, the overall normative purpose of WP2 is to explore the intersection between cultural rights of people with disabilities and cultural diversity in EU law.

Ten people participated to the first round of interviews of WP2³, drawn from 'policymakers' (broadly conceived of), including staff at the European Commission, the European Parliament and other bodies within the EU whose work either centres on or concerns the rights of persons with disabilities. Nine of these participants took part in interviews (with one completing a qualitative questionnaire) and all nine interviewees granted consent for archiving.

The second set of interviews of WP2⁴ were specifically designed, deployed and conducted with representatives from umbrella non-governmental organisations (NGOs) working on disability issues at the EU level and OPDs, also at the EU level. Ten interviews were conducted, with eight participants granting consent for archiving.

Another set of 10 interviews⁵ was carried out with a range of different stakeholders and policy makers dealing with cultural cooperation and disability within EU external relations. This set of interviews aimed to understand the extent to which the implementation of the CRPD and the UNESCO Convention on the Protection and Promotion of the Diversity of Cultural Expressions overlap at the EU level, considering also the effects that other international legal sources can have on the implementation of these conventions. Out of the 10 interviews completed, six participants granted consent for archiving.

³ These interviews are identified as the third dataset in Table 4.

⁴ These interviews are identified as the fourth dataset in Table 4.

⁵ These interviews are identified as the fifth dataset in Table 4.

3. DATA COLLECTION

This section presents how consent was dealt with and how data collection for qualitative research was carried out within the DANCING project.

3.1. Consent

In line with the DMP (Ferri, 2021), and in compliance with Maynooth University Research Ethics Policy (Maynooth University Academic Council, 2019) as well as with relevant research policies, explicit and informed consent was sought from all participants. An information sheet and a consent form were shared with all participants ahead of the interviews and focus groups. The information sheet detailed the DANCING project's aims. The consent form asked participants whether they consented to take part in the research and whether they agreed to an anonymised version of their transcript being shared with the IQDA for archiving. To express their consent, participants were asked to select between 'Yes/No' for various questions and sign the consent form. In some cases (e.g. where participants did not have access to a printer or scanner -which was often the case for participants working from home during the COVID-19 pandemic), participants signed the consent form digitally and returned it through their official email address. A blank copy of the standard consent form for interviews is attached as Annex I of this report. It is worth noting that the template was then tailored and adapted to suit different data collection phases, incorporating changes in accordance with the different types of participants in the study. A similar form (Annex II) was used for focus groups.

Participants were also asked in different sections of the consent forms whether they consented to take part in the research and have their anonymised data archived for future use. This enabled participants to join the research without having to opt-in to having their data archived. Consent was also discussed with participants at the beginning of the interview, and they were given the opportunity to ask any questions or address any concerns they may have had prior to the interview taking place, to ensure that their consent was fully informed.

Consent was logged for each participant as part of the data collection records. In cases in which consent was ambiguous (e.g. due to the consent form being partially completed), consent for archiving was not deemed to have been granted, hence the interview has not been archived. This precaution ensured a high standard of certainty in determining if a participant had given consent, in compliance with the ERC and MU good practices.

Notably for the purpose of this report, some of the interviewees withheld consent for archiving. On that basis, out of the 80 interviews completed, 64 were archived.

3.2. Data Collection

After obtaining consent, all the interviews were video- and audio-recorded through Microsoft Teams and stored in MP3 format, and subsequently transcribed *verbatim* by a transcription service. Transcribed interviews were checked by researchers for accuracy against original

audio recordings, with particular attention to specialist language (e.g. acronyms) that could be misheard by transcribers. A small number of interviews that were not conducted in English were transcribed and translated by members of the DANCING team with relevant linguistic knowledge. All transcripts and notes have been kept in Microsoft Word, and the interview transcripts have been coded through NVivo.

In a similar fashion, after obtaining consent, the focus groups were video- and audio-recorded through Microsoft Teams and stored in MP3 format. Subsequently they were transcribed by a member of the DANCING team. Reasonable accommodation was granted to those participants that required it to support their participation in the focus groups.

4. DATA PREPARATION AND ANONYMISATION

The main steps in the preparation of data for archiving were: (a) the development of a bespoke anonymisation plan to preserve the respondents' privacy and confidentiality as required under the consent agreement; and (b) an extensive data-anonymisation process. In compliance with best practices, data-anonymisation entailed the elimination of all participants' personal information, as well as information that could disclose the identity of participants. In several instances, it was deemed appropriate also to eliminate information that could identify third parties that came from participants' families or workplaces. Anonymisation was conducted with reference to IQDA best practice guidelines (Gray et al., 2011, p. 9). Further, the anonymisation process was carried out taking into account the main purpose of the qualitative research as well as research questions at the core of the DANCING project.

4.1. Identifying Information

As Dodds et al. (2021) point out, determining what constitutes identifying information is not an entirely straightforward consideration, also because it is shaped by various contextual factors relevant to the research, like the sensitivity of the topic discussed and the sampling approach. Consequently, in the process of anonymisation of the data collected in the DANCING project, a number of key considerations emerged when defining 'identifying' information. These included:

- **Specialised Roles:** Participants with highly specific roles or working for niche organisations are more easily identifiable. This was especially true for participants in countries where disability advocacy and/or inclusive arts practice are less developed or, for example, where the participant represented the only inclusive arts organisation. Given the small size of these organisations, specific reference to their activities would have made representatives identifiable. This applied mostly to WP1 interviews, therefore descriptions of organisation's activities were anonymised or removed from the archived versions of these transcripts.
- Lived Experience: Many involved in disability (and the arts) derive their expertise, among other sources, from personal experiences, making anonymisation more complex. This was also due to the fact that interviewees often extensively reflected on their own personal experiences or the experiences of those around them, making the participants more likely to be personally identified with their organisation. Hence, greater caution was exercised in removing identifying information that linked the individual's personal experiences to their organisation.
- Third-Party Information: It was not deemed appropriate to include personal information about friends, family, or colleagues that participants sometimes discussed as part of their reflections. This is because third parties had not themselves consented to take part in the research, particularly where this related to highly personal experiences of disability. However, third parties' reference was

retained when it was linked to public figures or institutions that were considered already in the public domain.

4.2. Anonymisation

As mentioned earlier, the anonymisation procedure was implemented in line with IQDA protocols (Gray et al., 2011). In order to grant a full and correct anonymisation, three factors have been taken into consideration: the risk of identification, the risk of harm and the sensitivity level (Geraghty, 2014). A tailored approach was employed to grant anonymity, and this involved individual scrutiny of each transcript. Given the complexity of the considerations to be made, this approach was deemed appropriate to balance the ethical and research needs.

In addition to this, anonymisation was granted through specific procedures:

- Marking changes: Identifying information was removed from the transcript, using tags to clearly designate edits and replacement text. Following IQDA recommendations, these were marked using '@@' at the beginning and '##' at the end of all changes to text.
- **Changelog:** A 'Changelog' was used to track changes to the manuscript. This followed a format and procedure suggested by IQDA guidelines which enables researchers to:
 - keep a record of changes made to the manuscript;
 - log queries and potential conflicts.

The use of a 'Changelog' allowed all changes to be easily reversible. This process was particularly useful, as it supported the achievement of a balance between efficient data collection on the one hand, and granting the anonymity of the participants on the other.

A QA process was also implemented in the overall data preparation process. The QA process identified and assessed risks of identification of data subjects from anonymised data and cross-checked anonymisation in order to prevent the singling out of individual data subjects and inference of any information about individuals from the data sets. Given that identifying information was mostly disclosed in WP1 interviews, an iterative approach was used to determine the appropriate level of contextual information to include. A more streamlined approach was followed for WP2 interviews, where the discussions did not include information related to the considerations made for the anonymisation process for WP1 interviews and where participants had been informed in advance (including in the relevant information sheets) that we would not name them but that we might name the institution/organisation that they worked for (such as the European Commission or the European Parliament) in research outputs.

5. DEPOSITING DATA WITH THE IRISH QUALITATIVE DATA ARCHIVE

Although the practice of archiving qualitative data has drawn considerable criticism (Parry and Mauthner, 2004; Bennett, 2021), since the early 2000's social researchers have recognised the relevance of storing research data for others to use (Corti, 2012; Geraghty, 2014; Diaz, 2021). The growing awareness of the necessity of preserving qualitative resources and an increasing interest in using existing data for research and teaching (Smioski, 2011) has supported funding bodies in strengthening initiatives to build up repositories and archives for social science data. DuBois et al. (2018) contend that a qualitative data set is rarely used to its full potential, and that secondary analysis of existing data can be useful for investigating different and new research questions. Further, they suggest that data sharing honours the time and expertise of participants by thoroughly analysing and co-disseminating knowledge (DuBois et al., 2018). By making data available and increasing the transparency and visibility of research processes, qualitative data archiving can dramatically reduce the costs of assessing empirically based analysis through replication (Swan and Brown, 2008, page 7). Elman et al. (2010) underline that data archiving is significant for multi-method studies, where the lack of data or difficulty in getting a comprehensive qualitative dataset may render the qualitative component a weaker dimension of the research.

The commitment of the DANCING project is to make qualitative data collected in the project available to other researchers and to ensure that that data can be re-used, in compliance with the good practices outlined by the ERC (ERC, 2022). This section specifies what steps have been followed when depositing data, specifically the methodology entailed, the documents deposited and the timeline of these tasks

5.1. Depositing Data

Anonymised data were archived with the IQDA, which is a central access point for qualitative social science data generated in Ireland. The IQDA is also a founding member of the Digital Repository of Ireland (DRI) which is a national trusted digital repository for Ireland's social and cultural data, and is available for use by the public, students and scholars.

In line with the DANCING DMP (Ferri, 2021), 12 months after the conclusion of the DANCING project (i.e. after 31st August 2026), the data will be searchable and accessible to researchers through the DRI website.

There were some particular considerations regarding archiving of questionnaires, which were overall of good quality but varied significantly in relation to their length and to the depth of the data they provided. In many cases questionnaires gave a considerable amount of information about the participant organisation's work and this was often accompanied by naming other organisations or describing the work of other organisations (and often providing website links). Ultimately, the decision was made not to archive questionnaires as that would have required, in most cases, to delete a considerable amount of the data to ensure anonymity. For these reasons, and in line with well-established practices mentioned in the

DMP, they were not archived as, after anonymisation, the data they provided would, in some cases, have been limited.

To comply with requirements for data to be FAIR (Findable, Accessible, Interoperable and Reusable), data were archived together with a set of accompanying files, including contextual documents to describe the overall DANCING project; metadata, that described each transcription of both interviews and focus groups; research instruments (i.e. the topic guide and a template of the consent form). As noted by Smioski (2011) '[d]ata documentation is essential for enabling sound secondary analyses of archived studies' as it 'establishes the bridge between primary researcher and secondary user, providing the latter with the metainformation necessary to understand the content and structure of the dataset, and the contextual information necessary for the user to comprehend the institutional, theoretical and methodical background of the study, to trace the process of data generation and processing throughout the research process and to learn about primary researcher's reflections on the research project'. Further, the Depositor Agreement with IQDA was signed and deposited together with the other documents.

Document type	Description
Contextual Document	This document provides an overview of the
	DANCING project and describes the individual
	subsets of interviews and focus groups (as
	indicated in Tables 4 and 5).
	In line with the view that data is an important
	scientific output, this document included a
	reference to the ERC grant number.
Metadata Spreadsheet	This document contains a range of descriptors
	for each individual transcription to be applied
	when uploading the file to the archive (see also
	Corti, 2012). Descriptors include filename, title,
	author, brief description and Humanities and
	Social Science Electronic Thesaurus (HASSET)
	subject descriptors (DRI, 2024).
Research Instrument	This document includes the topic guide and an
	example of the consent form signed by the
	participants
Depositor Agreement	This agreement allows IQDA to distribute the
	overall DANCING dataset for use under the
	Creative Commons Licence CC BY-NC-ND
	(Attribution-NonCommercial-NoDerivs). It also
	states that access to the data is strictly limited to
	parties engaged in educational research and
	teaching only, and it specifies that the data may
	not be disseminated until 12 months after the
	completion of the DANCING project (i.e. after 31
	August 2026).

Table 1: Overview of Documents Deposited with IQDA

A Data Availability Statement, informing the relevant public about where the above discussed research data are available and under which conditions it can be accessed (ERC, 2022), will be posted on the DANCING website.

5.2. Timeline of Archiving

Table 2 and 3 (below) show the timeline for completing archiving and the date each set of interviews and the two focus groups were deposited with the IQDA, beginning in June 2023 with the establishment of a protocol and ending with the depositing of interview groups 3-5 for the interviews, and for the focus groups.

		202	23							2024						
Interview group	WP	М	J	J	А	S	0	N	D	J	F	М	А	M	J	Deposited with IQDA
1	WP1															23/02/2024
2	WP1															12/03/2024
3	WP2															20/06/2024
4	WP2															20/06/2024
5	WP2															20/06/2024

Table 2: Timeline for Archiving and Depositing Interviews

Table 3: Timeline for Archiving and Depositing Focus Groups

		202	21							2024						
Focus Group	WP	М	J	J	A	S	0	N	D	J	A	S	0	N	D	Deposited with IQDA
1	WP1															16/10/2024
2	WP1															16/10/2024

Establishing protocol	
Archiving	
QA	

6. CONCLUDING REMARKS

The report outlines how the qualitative data within the DANCING project was collected, managed and archived. In outlining the processes followed and the approach adopted, the report explains how DANCING aligns with best practices in qualitative research and expounds how it complied with relevant research policies and practices, as well as with ERC requirements.

Further, the report aims to support other researchers in archiving qualitative data and ensuring comprehensive data management. In doing so, it provides a detailed description of how qualitative research was carried out within the DANCING project, considering both interviews and focus groups conducted within the remit of different WPs. The report also explains how consent was dealt with, and it entails a focus on how data was anonymised and subsequently archived. Every step of this procedure was compliant with all the ethical requirements of both the ERC and Maynooth University, and a balance was found between granting anonymity to the participants and not disclosing their private information, on one hand, and collecting and sharing full and rich data, on the other.

Table 4: Overview of Datasets

DATASET	WORK PACKAGE	PARTICIPANTS	START DATE	END DATE	DATA COLLECTED	CONSENT TO ARCHIVE	ARCHIVED
1	WP1	 Representatives of national OPDs Representatives of Deaf organisations Representatives of Arts and Disability (A&D) organisations 	Jun 2021	Aug 2023	41 interviews 23 questionnaires	34	34
2	WP1	 Representatives from EU-Level organisations representing cultural industries 	Jun 2023	Sep 2023	10 interviews	7	7
3	WP2	 EU Policymakers (such as EU Commission and Parliament) 	Dec 2023	Feb 2024	9 interviews 1 questionnaire	9	9
4	WP2	 Representatives from umbrella non- governmental organisations (NGOs) working on disability issues at the EU level Representatives from OPDs at the EU level 	Oct 2023	Jan 2024	10 interviews	8	8
5	WP2	 EU stakeholders dealing with cultural cooperation and disability within EU external relations 	Feb 2024	May 2024	10 interviews	6	6

Table 5: Overview of Archived Focus Groups

Focus Group	Work Package	Participants	Start Date	End Date	Consent to archive
1	WP1	People working on accessibility in arts organisations/institutions as well as in European projects on arts and disability	14 Dec 2021	14 Dec 2021	9
2	WP1	People working on accessibility in arts organisations/institutions as well as in European projects on arts and disability	15 Dec 2021	15 Dec 2021	11

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ANNEX I – INFORMATION SHEET FOR PARTICIPANTS TO INTERVIEWS

Draft: INFORMATION AND CONSENT FORM FOR RESEARCH PARTICIPANTS (INTERVIEWS)

Notes:

- This was the original template. The Project includes various sets of semi-structured interviews and this Template was used (with some adaptations) for each of them. It was also amended subsequently to make sure that it would be accessible for screen readers.
- The aim of this form is to facilitate informed consent by communicating with participants in language that they can understand. Not all participants will be native English speakers. Wherever necessary, this information sheet will be translated into an accessible language. Wherever it is necessary to accommodate different communication methods, accessible versions of all these forms will be made available in a wide variety of formats for participants (including electronic or Braille versions if required).



INFORMATION AND CONSENT FORM FOR RESEARCH PARTICIPANTS (Interviews)

Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths

DANCING

Dear [Participant's Name]

This letter is to invite you to take part in a study on the right of people with disabilities to participate in cultural life in Europe (DANCING), which is hosted by the Department of Law, Maynooth University, Ireland, funded by a European Research Council Consolidator Grant. Before you decide whether or not to take part, it is important for you to know why we are doing the research and what we would need from you. Please take time to read the following information carefully. If you are interested in taking part, but you need this information in a different language or format (including electronic, or Braille versions), please contact us to let us know.

Who is conducting this study?

[Name and title], is the principal researcher supervising a research team composed of colleagues [names].

What is the purpose of the study?

The purpose of this study and of the related data collection is to investigate the protection of the right of persons with disabilities to take part in cultural life including the recognition of disability identities, such as Deaf culture, as an essential aspect of enhancing cultural diversity in the European Union (EU) legal order. By taking part in cultural life, what we mean is the right to access cultural venues such as theatres, cinemas and museums, and to enjoy cultural materials, books, films and music in an accessible format as well as the right of people with disabilities to participate in cultural life as both amateur and professional artists. The study aims to contribute to the understanding of the extent to which persons with disabilities participate in cultural life and of how this impacts on cultural diversity. The study looks at what barriers exist to the exercise of the right to participate in cultural life for persons with disabilities, what support is needed, and what the European Union can do.

Who has approved this study?

This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee. You may have a copy of this approval if you request it.

Why have you been invited to take part?

You are invited to participate in this study because you are a key stakeholder in policy related to persons with disabilities and/or in cultural policies [in your country/ or in Europe]. By sharing your experiences with us, you will be helping Prof. Delia Ferri and her team members to better understand policy developments and future priorities in relation to participation of people with disabilities in cultural life.

What will happen if you take part?

You be interviewed by [name of team member] about participation by people with disabilities in arts and culture. [Reference to be inserted to how this will take place – MS Teams or face-to-face]. We anticipate that this interview will last approximately one hour. If you agree, your interview will be recorded, but your contribution will be anonymised and kept confidential. Afterwards it will be transcribed and this may be done by a professional transcriber. Both the recording and transcription will be stored on an encrypted computer. If we can facilitate your participation in another way, please let us know.

Do you have to take part?

No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to participate in this interview. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form (see overleaf) and given a copy and the information sheet for your records. If you decide to take part, you are still free to withdraw at any time without giving a reason and/or to withdraw your information up until such time as the research findings are published. A decision to withdraw at any time, or a decision not to take part, will not affect your relationship with Maynooth University.

Are there any risks associated with taking part?

We believe that there are no significant risks associated with participation.

What information will be collected?

We are interested to hear about your views on disability policies, access to culture, and disability identities, and how the European Union could improve participation in culture.

In compliance with Article 13 of the General Data Protection Regulation (GDPR) framework, Dr. Delia Ferri will be the person responsible for the collection of data. Dr. Ferri will be the data controller, that is, the person who determines the purposes for which, and the way in which, your personal data is processed. Dr. Delia Ferri can be contacted by email at <u>delia.ferri@mu.ie</u>, by telephone at 00353 (0)1 474 7210; by post at: Maynooth University, Department of Law, South Campus, Maynooth, Co. Kildare

Will your participation in the study be kept confidential?

Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identified at any time unless you wish to give explicit permission for this. All hard copy information will be held in a locked cabinet at the researchers' place of work, electronic information will be encrypted and held securely on Maynooth University PCs or servers and will be accessed only by the DANCING research team. No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

It must be recognised that in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances, the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

What will happen to the information which you give?

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server for five years (or longer if there are ongoing procedures such as audits, investigations or litigation). After five years, all data will be destroyed (by the Principal Investigator – Prof. Delia Ferri). Manual data will be shredded confidentially and electronic data will be reformatted or overwritten by Prof. Delia Ferri in Maynooth University.

We would like to place an anonymised version of the data on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it, if you agree to this. This would mean that, with your permission, once all the interviews are completed, the transcripts will be deposited in an archive, where other *bona fide* researchers may consult them. Before your interview is deposited in the archive, your name will be removed, and your comments will not be attributable to you. All other information that you have provided will be destroyed.

What will happen to the results?

The research will be written up and presented as deliverables of the project (i.e. summary report, presentation at national and international conferences and may be published widely in scientific journals and elsewhere). A copy of the research findings overall will be made available to you upon request.

What if there is a problem?

At the end of the interview, we will discuss with you how you found the experience. If you are unhappy with any aspect of this study, please first contact the Lead Researcher, Delia Ferri (Delia.Ferri@mu.ie). If you are unhappy about the process, you can also contact the Secretary of the Maynooth University Ethics Committee at <u>research.ethics@mu.ie</u> or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

If you wish to make a complaint about the data collection, you can contact the Maynooth University Data Protection Officer, Ms <u>Ann McKeon</u>, email: <u>dataprotection@mu.ie</u>, tel: +353 (0) 1 7086184

If there is a breach of the GDPR this will be notified to the Data Protection Officer (Ann McKeon) and reported to the Data Protection Commissioner (DPC), typically within 72 hours, unless the data was anonymised or encrypted.

The Data Protection Commission is located in 21 Fitzwilliam Square South, Dublin 2, Ireland, and can be reached at +353 (0)761 104 800, +353 (0)57 868 4800.

Any further queries? If you need any further information, you can contact me: Dr. Delia Ferri, Maynooth University Department of Law at (Delia.Ferri@mu.ie).

If you agree to take part in the study, please complete and sign the consent form overleaf.

Thank you for taking the time to read this

Consent form

I.....agree to participate in Dr. Delia Ferri's research study titled Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths (DANCING).

Please tick each statement below:

The purpose and nature of the study has been explained to me verbally and in writing. I have been able to ask questions, which were answered satisfactorily.

I am participating voluntarily.

I give permission for my interview with a member of the DANCING research team to be recorded

I understand that I can withdraw from the study, without repercussions, whether that is before it starts or while I am participating.

I understand that I can withdraw permission to use the data right up to publication.

It has been explained to me how my data will be managed and that I may access it on request.

I understand the limits of confidentiality as described in the information sheet

I understand that my data, in an anonymous format, may be used in further research projects and any subsequent publications if I give permission below:

I agree to quotation/publication of extracts from my interview I do not agree to quotation/publication of extracts from my interview	
I agree for my data to be used for further research projects I do not agree for my data to be used for further research projects	
I agree for my data, once anonymised, to be retained indefinitely in the Irish Qualitative Data Archive (IQDA)	

Signed	Date
51611Cu	Dutt

Participant Name in block capitals

You can sign the document using an electronic signature, or print it, sign it and scan it.

Then please email it to us at [insert Researcher's email address] in advance of your interview. If neither are possible for you, please let us know – we can also arrange to audio/video record your consent.

I the undersigned have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed..... Date.....

Researcher Name in block capitals

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at <u>research.ethics@mu.ie</u> or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information the Data Controller for this research project is Prof. Delia Ferri (delia.ferri@mu.ie). The controller's representative for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Two copies to be made: 1 for participant, 1 for PI

ANNEX II- INFORMATION SHEET FOR FOCUS GROUPS PARTICIPANTS



November 2021

INFORMATION AND CONSENT FORM FOR RESEARCH PARTICIPANTS (Focus Groups). Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths (DANCING)

Dear Focus Group Participant,

This letter is to invite you to take part in a Focus Group which is part of a study on the right of people with disabilities to participate in cultural life in Europe, hosted by the Department of Law, Maynooth University, Ireland, funded by a European Research Council Consolidator Grant. Before you decide whether or not to take part, it is important for you to know why we are doing the research and what we would need from you. Please take the time to read the following information carefully. If you are interested in taking part but find this form inaccessible or you need this information in a different language or format, please contact us to let us know.

Who is conducting this study?

Delia Ferri, Professor of Law at Maynooth University, is the principal researcher supervising a research team composed of colleagues including Dr Ann Leahy.

What is the purpose of the study?

The purpose of this study is to investigate the protection of the right of persons with disabilities to take part in cultural life, including the recognition of disability identities, such as Deaf culture, as an essential aspect of enhancing cultural diversity in the European Union (EU) legal order. By taking part in cultural life, what we mean is the right to access cultural venues such as theatres, cinemas, and museums, and to enjoy cultural materials such as books, films, and music in an accessible format. We also mean the right of people with disabilities to participate in cultural life as both amateur and professional artists and to be employed by cultural organisations. The study aims to contribute to the understanding of the extent to which persons with disabilities participate in cultural life and of how this impacts on cultural diversity. The study looks at what barriers exist to the exercise of the right to participate in cultural life, what support is needed, and what the European Union can do.

Who has approved this study?

This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee. You may have a copy of this approval if you request it.

Why have you been invited to take part?

You are invited to participate in a Focus Group as part of this study because you are a key stakeholder in cultural services or policies in your country and/or in policy related to persons with disabilities or Deaf people. By sharing your experiences with us, you will be helping Prof. Delia Ferri and her team members to better understand policy developments and future priorities in relation to participation of people with disabilities in cultural life.

What will happen if you take part?

You will be invited to participate in an online Focus Group with others to consider participation by people with disabilities in arts and culture. The Focus Group will take place using an online videoconferencing platform and we will send you a link by email, which will facilitate this. If you require any reasonable accommodation, please let us know.

We anticipate that this Focus Group will last approximately 1.5 to 2 hours and that it will be attended by approximately 7-10 people drawn from a selection of European countries. The language of the Focus Group will be English. The following are the ground rules for the conduct of the Focus Group to which you are asked to adhere:

- Respect the contribution of everyone and do not criticise other people's contributions.
- Participants agree to keep confidential responses made by all participants.
- There are no right or wrong answers to focus group questions.
- Out of respect for each other, only one individual shall speak at a time.
- Different viewpoints are welcome and everyone is encouraged to participate
- even when responses may not be in agreement with the rest of the group.

The Focus Group will be audio and video recorded, but afterwards your contribution will be anonymised and kept confidential. Afterwards it will be transcribed, and this may be done by a professional transcriber. Both the recording and transcription will be stored on an encrypted computer.

If we can facilitate your participation in another way, please do let us know.

Do you have to take part?

No, you are under no obligation whatsoever to take part in this research. It is entirely up to you to decide whether or not you would like to take part. However, we hope that you will agree to take part. If you decide to do so, you will be asked to sign a consent form (see to the end of this information sheet). If you decide to take part, you are still free to withdraw at any time without giving a reason and/or to withdraw your information up until such time as analysis of the data from the Focus groups has commenced. A decision to withdraw, or a decision not to take part, will not affect your relationship with Maynooth University.

Are there any risks associated with taking part?

We believe that there are no significant risks associated with participation.

What information will be collected?

We are interested in hearing about your views on access to culture and/or disability policies, and if you think the European Union could improve participation in culture by people with

disabilities and Deaf people. In compliance with Article 13 of the General Data Protection Regulation (GDPR) framework, Professor. Delia Ferri will be the person responsible for the collection of data. Professor Ferri will be the data controller, that is, the person who determines the purposes for which, and the way in which, your personal data is processed. Prof. Delia Ferri can be contacted by email at <u>delia.ferri@mu.ie</u>.

Will your participation in the study be kept confidential?

All participants in the Focus Group are asked to keep others' contributions confidential. All information that is collected about you by the research team during the course of the research will be kept confidential. No names will be identified at any time by the research team unless you wish to give explicit permission for this. All hard copy information will be held in a locked cabinet at the researchers' place of work, electronic information will be encrypted and held securely on Maynooth University PCs or servers and will be accessed only by the DANCING research team. No information will be distributed by the research team to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

It must be recognised that in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances, the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

What will happen to the information which you contribute at the Focus Group?

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server for five years (or longer if there are ongoing procedures such as audits, investigations, or litigation). After five years, all data will be destroyed (by the Principal Investigator – Prof. Delia Ferri). Manual data will be shredded confidentially, and electronic data will be reformatted or overwritten by Prof. Delia Ferri in Maynooth University.

If you agree to this, we would like to place an anonymised version of the data on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it. This would mean that, with your permission, once all aspects of this study are completed, the transcripts of Focus Groups will be deposited in an archive, where other bona fide researchers may consult them. Before the transcript of the Focus Group is deposited in the archive, your name will be removed, and your comments will not be attributable to you. All other information that you have provided will be destroyed.

What will happen to the study results?

The research will be written and presented as deliverables of the project (i.e., summary report, presentation at national and international conferences; it may be published widely in scientific journals and elsewhere). A summary of the research findings overall will be made available to you on request.

What if there is a problem?

At the end of the Focus Group, we will discuss with you how you found the experience. If you are unhappy with any aspect of this study, please first contact the Lead Researcher, Delia Ferri (<u>Delia.Ferri@mu.ie</u>). If you are unhappy about the process, you can also contact the Secretary of the Maynooth University Ethics Committee at <u>research.ethics@mu.ie</u> or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

If you wish to make a complaint about the data collection, you can contact the Maynooth University Data Protection Officer, Ms. Ann McKeon, email: <u>dataprotection@mu.ie</u>, telephone: +353 (0) 1 7086184. If there is a breach of the GDPR this will be notified to the Data Protection Officer (Ann McKeon) and reported to the Data Protection Commissioner (DPC), typically within 72 hours, unless the data was anonymised or encrypted. The Data Protection Commission is located in 21 Fitzwilliam Square South, Dublin 2, Ireland and can be reached at +353 (0)761 104 800, +353 (0)57 868 4800.

Any further queries? If you need further information, you can contact Dr Ann Leahy or Prof. Delia Ferri, Maynooth University Department of Law at (<u>relevant email addresses</u>).

If you agree to participate in the study, we need you to confirm this by completing and signing the consent form overleaf. There are a number of ways that you can do so:

You can type your name on the form, or You can sign it using an electronic signature, or You can print it out, sign and complete it and then scan it.

Please then email it back with an email message that confirms your consent to participate in the study.

Thank you for taking the time to read this. If you are happy to proceed, please complete the Consent Form (below).

Consent form

I [Insert Name Here] agree to participate in Prof. Delia Ferri's research study titled Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths (DANCING). Please read the following statements and delete 'yes' or 'no' as applicable:

(1) The purpose and nature of the Focus Group and the study have been explained to me verbally and/or in writing. I have been able to ask questions, which were answered satisfactorily **Yes / No**

(2) I am participating voluntarily Yes / No

(3) I agree to adhere to the ground rules for the Focus Group Yes / No

(4) I give permission for my contributions to the Focus Group conducted by members of the DANCING research team to be audio/ video recorded **Yes / No**

(5) I understand that I can withdraw from the study, without repercussions, whether that is before it starts or while I am participating **Yes / No**

(6) I understand that I can withdraw permission to use the data up to the point that my information is analysed (or, if earlier, publication or deposit in the Irish Qualitative Data Archive (IQDA)) **Yes / No**

(7) It has been explained to me how my data will be managed and that I may access it on request **Yes / No**

(8) I understand the limits of confidentiality as described in the information sheet Yes / No

(9) I agree to quotation/publication of my contributions to the Focus Group in an anonymous format. **Yes / No**

(10) I understand that **if I give permission below** my data, in an anonymous format, may be used **in further research projects** and in any subsequent publications. **Yes / No**

I agree for my data to be used for further research projects. **Yes / No** I do not agree for my data to be used for further research projects. **Yes / No**

I agree for my data, once anonymised, to be retained indefinitely in the Irish Qualitative Data Archive (IQDA). **Yes / No**

Next, you can sign this document by typing your name, by using your electronic signature, or by printing it, completing it, and scanning it. If none of these options is possible for you, please

let us know – we may also be able to arrange to audio/video record your consent. Once signed, please email it back to <u>Ann.Leahy@mu.ie</u> to confirm your agreement to participate in advance of the Focus Group.

Please sign here:

Please Insert your Job Title and Organisation's Name here:

Please insert date here:

I the undersigned Researcher have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed	Date

Researcher Name in block capitals

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at <u>research.ethics@mu.ie</u> or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information, the Data Controller for this research project is Prof. Delia Ferri (<u>delia.ferri@mu.ie</u>). The controller's representative for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at <u>ann.mckeon@mu.ie</u>. Here you can find <u>Maynooth University Data Privacy policies</u>.