Exploring Adult Adoptees' use of DNA Testing as a Method of Adoption Tracing

Denise Linehan

CARL Research Project

in collaboration with

Aitheantas-Adoptee Identity Rights



Name of student(s):	Denise Linehan
Name of civil society organisation/community group:	Aitheantas-Adoptee Identity Rights
Name of community group liaison person:	Maree Ryan O'Brien
Academic supervisor(s):	Olwen Halvey
Name and year of course:	Master of Social Work, 2021
Date completed:	27/04/218

What are Community-Academic Research Links?

Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grassroots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (<u>www.livingknowledge.org</u>).

What is a CSO?

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

Why is this report on the UCC website?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

How do I reference this report?

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: <u>http://www.ucc.ie/en/scishop/completed/</u> [Accessed on: date].

How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?

The UCC CARL website has further information on the background and operation of Community-Academic Research Links at University College Cork, Ireland. <u>http://carl.ucc.ie</u>. You can follow CARL on Twitter at @UCC_CARL. All of our research reports are accessible free online here: <u>http://www.ucc.ie/en/scishop/rr/</u>.

CARL is part of an international network of Science Shops called the Living Knowledge Network. You can read more about this vibrant community and its activities on this website: http://www.scienceshops.org and on Twitter @ScienceShops. CARL is also a contributor to Campus Engage, which is the Irish Universities Association engagement initiative to promote community-based research, community-based learning and volunteering amongst Higher Education students and staff.

Are you a member of a community project and have an idea for a research project?

We would love to hear from you! Read the background information here <u>http://www.ucc.ie/en/scishop/ap/c&vo/</u> and contact us by email at <u>carl@ucc.ie</u>.

Disclaimer

Notwithstanding the contributions by the University and its staff, the University gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Client Group, or users, to ensure that any outcome from the project meets safety and other requirements. The Client Group agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed to a very high standard and to the satisfaction of the Client Group

Declaration of Originality

"This is to certify that this dissertation: **Exploring Adult Adoptees' use of DNA Testing as a Method of Adoption Tracing** is my own and has not been submitted for another degree, either at University College Cork or elsewhere. This is submitted to the School of Applied Social Studies, University College Cork as part of the Master of Social Work programme.

All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism. The dissertation has been submitted to TurnItIn in advance of the submission deadline and suggested changes have been addressed.

Name:_____

Date: _____

Abstract

Advances in science and technology have influenced several facets of modern society. Specifically, the emergence of DNA testing or Direct to Consumer Genetic Testing (DTC-GT). In addition, the development of social media platforms has made the ability to connect with others instantaneous, anonymous, and effortless. Regarding the field of adoption these resources have changed the practice of search and reunion for birth parents, adoptees, and adoptive families in Ireland. In view of these novel resources for adoption services, it is essential to critically evaluate their utility. Hence, in collaboration with Aitheantas-Adoptee Identity Rights, this dissertation explored adult adoptees' use of these methods for tracing biological relatives by means of primary research. Initially an online Google Form questionnaire was distributed which received 48 individual responses. Thereafter, follow up interviews were conducted online over MS Teams with just 6 participants, due to the scope of this minor dissertation. The participant's journey for connection, access to birth information and reunion in several cases informed this dissertation. The findings indicate that the above methods proved to be a positive resource for several adoptees. Adoptees also acknowledged that there are limitations to using such resources. With regards to DNA testing, results may not yield close familial matches and can be difficult to interpret in some instances. Given this, adoptees highlighted the emotional element of these contemporary methods of adoption tracing. Consequently, it emerged that further consideration and revision as to the current search and reunion practices mentioned above need reform in the Irish context.

Dedication

This dissertation is dedicated to my late uncle Dr. John Linehan.

"A Scholar and a Gentleman" (Shaplin, 1991).

Acknowledgements

Thank you all for the encouragement and validation over the last two years:

Firstly, to my tutor Olwen Halvey for the endless support and guidance,

To my CARL partner, for the check-ins and reassurance,

To my parents for giving me the opportunity to embark on this career path and for putting a roof over my head!

To my brother and dissertation editor Kevin, current PHD student and future Dr. Linehan

To my confidant, comrade, and life coach,

Elaine Hanley for keeping me going through the difficult times,

To my better half Iarfhlaith, for reminding me of my purpose remaining patient and inserting the commas I overlooked,

Finally, to the 'Last Minute Larry's', you know who you are!

Table of Contents

UCC CARL	i
CARL Information	.ii
Declaration	.iii
Abstract	iv
Dedication	v
Acknowledgements	.vi

Table of Contents

Chapter One: Introduction	1
1.1 Introduction	1
1.2 Research Title	1
1.3 Background to the Research	1
1.4 CARL Partner	2
1.5 Research Rationale	2
1.6 Research Aim	2
1.7 Research Objectives	3
1.8 Research Questions	3
1.9 Chapter Outline	4
1.10 Glossary of terms	4
Chapter Two: Literature Review	6
2.1 Introduction	6
2.2 Ireland's History of Adoption	6
2.3 Development of Adoption Legislation	7
2.3.1 Information and Tracing Bill (2016)	8
2.4 The Emergence of DTC-GT	9
2.4.1 Relevance of DTC-GT for Adoptees	9
2.5 Adoptees experiences of DTC-GT	10
2.5.1 Data usage and efficiency of DTC-GT	11
2.6 Other Components in the Search Process	12
2.6.1 Social Media, an added tool for adoption tracing?	12

	2.7 Conclusion	13
	Chapter Three: Methodology	15
	3.1 Introduction	15
	3.2 Epistemology	16
	3.3 Theoretical Perspective	16
	3.4 Community Based Participatory Research (CBPR)	17
	3.5 Research Methodology	17
	3.6 Research Methods	18
	3.7 Sampling and Data Collection	18
	3.7.1 Sampling	18
	3.7.2 Data Collection	19
	3.8 Data Analysis	19
	3.9 Ethical Considerations	20
	3.10 Researcher Reflexivity	21
	3.11 Challenges and Limitations	22
	3.12 Conclusion	22
Cha	pter Four: Findings	24
4.	1 Introduction	24
4.	2 Quantitative Data Findings	24
Q	ualitative Findings: Thematic Analysis	30
4.	3.1 Theme One: DNA Testing in the Search for Connection	30
4.	3.2 Discussion	30
4.	4 Theme Two: Adoptee's Assessment of DNA Testing	31
4.	4.1 Advantages of DNA testing for tracing	31
4.	4.2 Criticism	32
4.	4.3 Discussion	33
4.	5 Theme Three: 'Support is there but it isn't visible'- Adoptee's Proposals	34
4.	5.1 Perception of the Role of Social Work in Tracing	35
4.	5.2 Discussion	36
4.	6 Conclusion	37
Cha	pter Five: Conclusion	39
5.	1 Introduction	39
5.	2 Concluding Comments	39
5.	3 Recommendations	40
5.	4 Future Research	41

41
43
67
69

List of Figures

Figure 3.1: Chapter 3- Methodology
The 'Four Elements' of this research topic
Figure 1: Chapter 4- Findings
Awareness of DNA testing
Figure 2: Chapter 4- Findings
Methods of Adoption Tracing
Figure 3: Chapter 4- Findings
Outcome of DNA Testing Results40
Figure 4: Chapter 4- Findings
Tracing Biological Relatives with social media41
Figure 5: Chapter 4- Findings
Emotional Impact42
Figure 6: Chapter 4- Findings
Support Services



Chapter One: Introduction

1.1 Introduction

Firstly, acknowledgement of the exceptional response received from adult adoptees in relation to the research topic is essential. As the researcher, I wish to extend my gratitude to those who participated in both the questionnaire and interviews. This response truly reaffirmed the purpose and importance of this study. Considering the scope of this dissertation, only the questionnaire data will be presented exclusively in this study. The interview data will be presented at a later date, through a second phase of analysis. This chapter introduces the reader to the topic, provides a background to the research undertaken and offers the rationale for conducting this research study. A brief introduction to *Aitheantas-Adoptee Identity Rights*, whom I collaborated with as part of the Community Academic Research Links (CARL) initiative, is also presented. Finally, the research aims, objectives and research questions informing the subject are presented, including an outline of the subsequent chapters.

1.2 Research Title

'Exploring Adult Adoptees' use of DNA Testing as a method of Adoption Tracing'.

1.3 Background to the Research

Adoption has historically been a matter of contention in the Irish context. It is both a deeply personal and sensitive issue for many people. The issue of *Information and Tracing (2016)* currently awaits a solution. The law and legislation governing the access to identifying information is quintessentially archaic, dating back to 1952. Given the rapid advancements in science and technology, the issue of accessing birth information has changed in some respects. As such the search for family history has become more efficient for birth parents and adoptees. The emergence of DNA testing has brought a new perspective to the search and reunion process. In 2019, more than 26 million people participated in Direct-to-Consumer Genetic Testing (DTC-GT) services (Regalado, 2019). More specifically, this online resource can potentially unearth ancestral, ethnic and health information for adult adoptees.

1.4 CARL Partner

Aitheantas-Adoptee Identity Rights is a community group concerned with campaigning for Irish adoptees' right to health, heritage, and history information. Aitheantas is a Gaelic term, the English translation is identity (Aitheantas, 2021). "*Identity refers to those attributes and qualities that enable us to recognize an individual or collective from others*" (Tamimi, 2017, p.1). A report conducted by *Aitheantas* titled, "*Adoptees Voices*" is due for publication. The report reaffirms the need for adoptees to openly access birth information. In addition, *Aitheantas* further highlighted the need for change in Irish adoption legislation with the campaign "*Repeal the Seal, Open the Archive*" (2020). Furthermore, in October (2020), *Aitheantas* advocated for the mental health of Irish adoptees prior to the release of the Commission of Investigations Report into the Mother and Baby Homes (2021). As a result, the HSE National Counselling Service provided free HSE counselling support for former Mother and Baby Home residents.

1.5 Research Rationale

The subject of this dissertation originated from a discussion which related to Irish adoptees' access to birth information. This led to the emergence of the idea that adoptees are essentially purchasing their identity by means of DNA testing. Given this, I conducted a preliminary literature search and established that a small number of studies existed on the topic. Moreover, the literature reviewed identified the need for further research studies with the view of understanding adoptees' experiences in more depth. Irish literature regarding this matter is limited. Therefore, international studies informed this dissertation. Since starting the MSW, I aimed to apply for a CARL research project to make a valuable and worthwhile impact in relation to my local community and society on a broader level. With regards professional development, this dissertation has contributed to the development of my social research skills.

1.6 Research Aim

This research aims to explore DNA Genealogy Testing as an adoption tracing method, specifically from the perspective of adult adoptees. It hopes to assess adoptees' use of social

media as an additional tracing resource and address whether psychosocial support would be useful during the process.

1.7 Research Objectives

The main objectives of this research are outlined as follows:

- 1. To provide a brief overview of adoption legislation, policy, and practice in Ireland.
- 2. To examine international research and studies pertaining to DNA Genealogy testing as a means of further reference.
- 3. To explore the method of DNA Genealogy testing used to trace family history by discussing the experience with a sample group of adult adoptees.
- 4. To understand the factors that contributed to adult adoptees' decision to use DNA Genealogy testing for tracing biological relatives.
- 5. To examine popular discourses in relation to adoptive practices in Ireland to better understand the world of adoptees further, in particular social media.
- 6. To identify a way to add a psychosocial support context to the DNA Genealogy testing process used by Irish adoptees.

1.8 Research Questions

- 1. What was the experience of adult adoptees using DNA Genealogy testing for adoption tracing in Ireland?
- 2. What reasons can be identified as contributing factors for using DNA Genealogy testing?
- 3. Was social media helpful for Irish adoptees as an additional means of tracing their biological relatives?
- 4. How could psychosocial support be established for adoptees participating in the DNA Genealogy testing process in Ireland? What is the role of social work in adoption tracing?

1.9 Chapter Outline

• Chapter One: Introduction

This provides the reader with background knowledge of the topic and community partner organisation, *Aitheantas-Adoptee Identity Rights*. The value of this dissertation, research aims, objectives and research questions are also presented.

• Chapter Two: Literature Review

Ireland's history of adoption legislation, current research on Direct-to-Consumer Genetic Testing (DTC-GT) technology and relevant theories are reviewed. Given this, adoptees experience of DTC-GT on an international scale are also outlined.

• Chapter Three: Methodology

This outlines epistemological positioning and theoretical perspectives of the research. The methodology, data collection, ethical considerations, reflexive positioning of the researcher, limitations of the research and challenges will also be addressed.

• Chapter Four: Findings and Discussion

This examines the findings from the UCC Supplied Version of Google Forms questionnaire distributed. These findings will be discussed in relation to the literature cited in 'Chapter Two'.

• Chapter Five: Conclusion and Recommendations

This presents the reader with a number of recommendations drawn from the research findings. In addition, areas for future research potential are included. To conclude, a reflection of my research experience is offered.

1.10 Glossary of terms

Regarding the topic, the following terms will be used interchangeably throughout this dissertation:

DNA Testing
DTC-GT- Direct to Consumer Genetic Testing
DNA Genealogy Testing



Chapter Two: Literature Review

2.1 Introduction

Numerous studies have previously explored the topic of DNA testing or the alternative term, "*Direct to Consumer Genetic Testing*" (DTC-GT), which is also commonly used in the literature (Roberts et al, 2017, p.1). For the purpose of this review, I will use the acronym, DTC-GT. I aim to examine the practice of DTC-GT and the use of social media as a means of adoption tracing to gain a greater understanding of modern search and reunion methods. Triseliotis et al (1997) stated that a reflection of the past is pertinent as it allows for a critical discussion of the topic, which seeks to inform present and future practice. In light of that knowledge, this review will firstly provide a brief overview of Irish adoption legislation. Secondly, an explanation of DTC-GT will be presented to the reader. As research regarding DTC-GT is limited in an Irish context, I will analyse the key debates arising from international literature, primarily conducted in the United States. Finally, I will discuss the use of social media subsequent to DTC-GT as a means of adoption tracing.

2.2 Ireland's History of Adoption

20th century Ireland was a tremendously divergent setting than the present time. It was a time of religious decree, with Catholicism featuring significantly in both public and private lives of Irish citizens. Given this it can be argued that *"Irish families were less willing to provide a home and support to a daughter who had given birth outside marriage"* (Commission of Investigation, 2021, p.59). Such societal attitudes led to the formation of an Ireland where children born to single mothers encountered fierce scrutiny (Powell & Scanlon, 2016). Children who were adopted prior to 1952, largely experienced significant challenges in tracing their ancestry. Consequently, adoption practices emerged which were informal and, in some cases, illegal. With regards to illegal adoptions, the falsification of records is evident for some adopted adults which indicates this is a topic pertaining to human rights (O'Brien & Mitra, 2018). During the late 20th century, Irish society began to evolve. Fortunately, this evolution paved the way for the topic of adoption to enter the field of academic literature. However, O'Brien & Mitra (2018) suggest that the discourse amongst society was still dominated with perceptions of illegitimacy and unmarried women, nonetheless.

2.3 Development of Adoption Legislation

Prior to 1952, adoption legislation in Ireland was non-existent. Indeed McCaughren & Lovett (2014) suggested that "secrecy was the cornerstone of adoption" (p.239). Irish society overlooked the existence, persistence, and presence of such a practice, as silence prevailed amongst the dominant discourses and social attitudes. In effect, adoption arrangements were considered to be "insecure" as parental rights, responsibilities and duties were not provided for on a statutory basis (O'Halloran, 1994, p. 7). Therefore, the Adoption Act (1952) paved the way for long-awaited adoption legalisation. This led to the subsequent implementation of the Adoption Act (2010), which is the current iteration of legislation governing adoption.

Under the 1952 Adoption Act, the idea of the adopted person tracing their biological relatives was not considered. Instead, a "*clean break and closed*" adoption was preferred (O'Brien, 2013). This closed system of adoption continued under the Adoption Act (2010) which consolidated prior legislation. In order to access birth information, adoptees are required to apply to the Adoption Authority of Ireland (AAI) and request permission to obtain such documents (Section 86, Adoption Act 2010). This request is assessed by the (AAI) which provides adoptees with information that is "*non-identifying*" in relation to their biological parents (McCaughren & Lovett, 2014, p. 243). Furthermore, it is apparent amongst literature that the Adoption Act (2010) prompted controversy as a request for adoptees to sign a "*no-contact*" veto was put forward (Redmond, 2018, p.230). However, this was disputed and at present, a solution is required to establish a process that will protect the rights of both birth mothers and adoptees. The recent Commission of Investigations Report (2021) further reaffirmed this point.

However, McCaughren & Ni Raghallaigh (2015) suggest that "an open approach to domestic adoptions" has surfaced in Ireland (cited in Christie, et al., 2015, p.76). Additionally, O'Brien (2013) comments that open adoption practice is evident, albeit on an informal basis. Similarly, McCaughren & Lovett (2014) note the advantages of open adoption and make reference to the issue of information and tracing in the Irish milieu with respect to privacy and identity rights.

2.3.1 Information and Tracing Bill (2016)

"The issue of adoptees, birth mothers and siblings seeking access to birth or adoption records or seeking to make contact is fraught with difficulties and conflicting interests" (Law Reform Commission [LRC], 2000, p.14).

With regards to this dissertation, reference to information and tracing legislation is essential. It is important to note that the law is currently the same as in 1952 on this matter also. For instance, the *Information and Tracing Bill (2016)*, proved controversial as the unrestricted release of birth information to adoptees was deemed to be *"unconstitutional"* (O'Mahoney et al., 2019, p.3). As such, this proposed legislation lapsed, as the conditions were subject to debate. As such, O'Mahoney et al (2019) comment that the Irish Constitution and the EU General Data Protection Regulations (GDPR) are due further consideration regarding this matter. At present, *"numerous other European Union jurisdictions provide all adopted adults with access to their identity"* (O'Mahoney et al., 2019, p. 8).

Moreover, O'Brien (2013), suggests that Ireland's information and tracing legislation is inherently out-dated, and reform is warranted. As such Canada, New Zealand, and Australia have surpassed Ireland in terms of adoption legislation. Thus, Redmond (2018) asserts that this issue is "a serious and sustained abuse of human rights" (p.151). The concern arising here relates to balancing a birth mothers right to privacy and confidentiality and adoptees right to access identifying information. Furthermore, Geissinger (1984) suggests that access to birth and adoption information can positively contribute to an adoptee's sense of self. As O'Brien (2013) contends "for many it is simply seen as a basic human right to have such information" (p. 24). Moreover, Geissinger (1984) notes that current legislation in Ireland breaches basic human rights. According to the Law Reform Commission (2000) these include the UN Convention on the Rights of the Child and the European Convention on the Rights of the Child (LRC, 2000).

2.4 The Emergence of DTC-GT

As traditional genealogical techniques merged with "*genomic testing*" methods, DTC-GT became available on a private basis (Casas, 2014, p.134). According to Oh. B (2019):

Conventional genetic testing is a process in which clinicians take samples from patients as clinically needed, send them to a laboratory for genetic testing, and discuss the test results with patients. Direct-to-consumer (DTC-GT) is different from conventional genetic testing in that consumers learn about DTC- GT from TV commercials, the internet, or in-store advertising, and request the tests to be performed by DTC companies by their own choice (Oh. B, 2019, p.1).

As such, in excess of 26 million people engaged in DTC-GT during 2019 (Regalado, 2019). Companies such as AncestryDNA, 23andMe and My Heritage made DTC-GT kits readily available worldwide. These kits have provided customers with the opportunity to discover details about family history, ancestral and ethnic origins as well as details regarding geographical regions (AncestryDNA, Privacy Statement, 2021).

2.4.1 Relevance of DTC-GT for Adoptees

It is apparent from the literature that many adoptees face limited knowledge relating to their ancestry, ethnicity, and genetic health history. McCaughren & Lovett (2014) suggest that historically Ireland's closed adoption system has led to a suppression of adoptees "*natural curiosity*" (p.77). For instance, due to illegal birth registration, missing adoption files and scarce records the search process can prove challenging. As a result, the development of DTC-GT is an opportunity to "*attempt to fill gaps in an adoptees personal narrative or sense of self*" (Cai et al., 2020, p. 462). According to Lee et al (2020) adoptees have conventionally availed of statutory adoption tracing methods. For example, adoption social workers provide assistance with search and reunion as well as mediation and counselling support where needed (Adoption Authority of Ireland, 2021). Although, it is evident that the efficiency and availability of DTC-GT has proved to be a favourable alternative for adoptees in some instances (Baptista et al., 2016, Childers, 2017, Strong et al., 2017).

2.5 Adoptees experiences of DTC-GT

A study by Baptista et al (2016) (n=1670) revealed that DTC-GT testing acted as a useful adoption tracing resource. The study outlined various reasons for engaging in DTC-GT, which included, limited family health information, potential risk of genetic disease, exploration of ancestry, and a desire to reconnect with biological relatives (Baptista, et al., 2016). In subsequent studies reviewed, these reasons emerged as common motivating factors for adoptees (Strong et al., 2017, Childers, 2017, Lee et al, 2020, Cai et al, 2020, Allyse et al, 2018, Casas 2018). Furthermore, Cai et al (2020) recommended the need for additional research studies concerning adult adoptees in particular to examine the "*why and how*" factors that led adoptees to undertake DNA testing (p.11).

Strong et al (2017) (n=17) noted the importance of sharing the results with children and future generations of adoptees as significant. Whereas Childers (2017) further examined adoptees use of DTC-GT from an emotional perspective wherein "adoptees were noted to have strong emotional responses to DTC-GT results" particularly regarding heritage (p.29). A study conducted by Allyse et al (2018) expressed the need for support to be considered for those who undertake DTC-GT. Recommendations included "counselling" and "follow up" support as those engaging in testing could be in a vulnerable position depending on the results (Alyse et al, 2018, p. 118). Previous studies relating to the impact of DTC-GT on mental health concluded that the process did not cause significant distress to consumers. Although Childers (2017) emphasises that these studies were general and not specifically focused on adoptees.

According to Childers (2017), adoptees' expectation of DTC-GT results led to "feelings of frustration and disappointment" in (21.43%) of cases. This was as a result of not finding biological relatives and also receiving little feedback from relatives once some adoptees had initiated contact. It emerged that the search for a sense of personal identity also encouraged adoptees' use of DTC-GT. Childers (2017) suggests that "the impact of unknown family history may impact adoptees in several aspects of their lives including mental health" (p.9). Similarly, McCaughren & Lovett (2014) comment that adoptees have previously made reference to the impact of missing family history. However, Corder (2012) explains that "identity formation can be a major challenge for adoptees, but most adult adoptees adjust well" (p.1).

The concept of identity formation features widely in the work of Erikson (1950) which holds the view that an individual's identity develops in adolescence. Contrary to this, several studies critique the application of Erikson' identity concept to adult adoptees. For instance, Grotevant (1987) suggests that identity is subject to change. With regards to adult adoptees this suggests that personal identity formation is influenced by other events and contexts (Grotevant,1987). Correspondingly, Baptista et al (2016), suggested that "*a person's identity can be shaped by his or her ethnicity and ancestry, and lack of information in this area may be a concern for some adoptees*" (p.930).

Furthermore, May et al (2016) raised an interesting question as to adoptees risk in terms of healthcare. Lacking information about one's own family, health and heritage could have long term health implications the study suggested. Lee et al (2020) also concluded that the adoptee population are potentially at risk in terms of healthcare. As a result, the study emphasised the need to address adoptees' identity rights to *"improve health outcomes"* (Lee et al., 2020, p.11). Additionally, the study cited research, education, and risk assessments as potential tools to develop *"guidance surrounding clinical genetic testing for adoptees"* (Lee et al., 2020, p.11).

2.5.1 Data usage and efficiency of DTC-GT

Casas (2018) noted that DTC-GT is open to critique. Although it is readily available in recent years and in terms of affordability, it is generally deemed to be affordable (Casas, 2018). However, an important point to note is that the efficacy of such testing is imperative in terms of its "clinical validation, detection rate, negative predictive value, and its interpretation and classification of gene variants" (Casas, 2018, p. 134). It is important to include this in terms of objectivity. Moreover, May (2016) notes that genetic testing for medical issues is strictly regulated in comparison to commercial DTC-GT testing. Strong et al (2017) emphasised how participants expressed concerns about the use of their data. Similarly, Lee et al (2020) found that privacy was an issue of notable concern for adoptees. Conversely Baptista et al (2016) assert that "adoptees were less concerned about the privacy of their genetic information" (p.930). In this regard, Baptista et al (2016) suggest that adoptees' difficulty with accessing birth information prompts adoptees to be in favour of open practice and "easier access to adoption records" (p.930).

2.6 Other Components in the Search Process

A question which emerged from researching this topic pertains to the role that social media has in the lives of adult adoptees who engage in DTC-GT. The role of social media is due consideration as it can form part of "*how*" adoptees trace their biological relatives in conjunction with DTC-GT results (Cai et al, 2020, p.11). In the digital world that is rapidly advancing as mentioned earlier, the role of social media is crucial in several aspects of everyday living (O'Brien, 2013).

2.6.1 Social media, an added tool for adoption tracing?

According to Lee et al (2020) adoptees stated that DTC-GT provided them with more "*control*" in terms of adoption tracing (p. 461). It enabled adoptees to access health information inadvertently without initiating contact with biological families. This provided adoptees with the choice to contact family on an individual basis. Additionally, the 2013 survey "*Untangling the Web II*" revealed that social media usage:

Allows for connection but feels less intrusive and sometimes less personal than visits of phone calls. The benefits of the Internet outweigh the risks. (Whitesel & Howard, 2013, p.27).

Moreover, social media is a tool that can be useful in the search for family relatives and history in conjunction with DNA results. The instant access that social media and the internet provides can assist adoptees with access to information relating to their family history on a private basis (McCaughren & Lovett, 2014). This resource allows adoptees the opportunity to potentially gather information quicker than utilising statutory or agency channels in some regards.

Fursland (2010) indicates this rapidly developing search tool can have positive and negative implications for adoption practices. As Shier (2019) points out, much of the literature is focused on the negative impact of social media. Thus, Shier (2019) established that in terms of intercountry adoption social media plays a vital role regarding *"both initiating and maintaining birth family contact"* (62). It appears that adult adoptees also regularly engage with social media as a means of support and an opportunity to speak to other adoptees (Jones, 2012 cited in O'Brien 2013). Research indicates that online support networks are a positive resource available for adoptees (O'Brien, 2013).

However, it is essential to recognise that the availability of these private search methods can pose risks. These risks as identified by McCaughren & Lovett (2014) can include the vulnerability of adoptees "as they are working without the support and counselling that a social worker mediated trace could provide" (p.247). Furthermore, Allyse et al (2018) explains that "several DTC-GT companies encourage their customers to engage with online social media platforms", however this is not a compulsory requirement (p. 134). Jones (2012) offers a critique of social media in relation to online bullying and the element of emotional vulnerability that adoptees can experience (cited in O'Brien, 2013).

2.7 Conclusion

Although this dissertation is primarily focused on the use of DTC-GT in relation to adult adoptees, a brief overview of adoption history and legislation situates the topic within a wider context. The key debates pertaining to adoption legislation were outlined relating to *Information and Tracing (2016)*. O'Brien and Mitra (2017) noted in a step-by-step review of adoption research from (1952-2017), that there is generally a limited research base on Irish adoption. Considering this, my literature search relating to DTC-GT testing further corroborated this research as it emerged that studies in the Irish context are limited. I have included the results collected from screening databases which focus, specifically on adoptees. The chapter concluded with reference to the implications of social media for adoption tracing, more specifically in conjunction with DTC-GT. The next chapter informs the reader as to the methodology underpinning this dissertation. On this basis, the epistemology, theoretical perspective, methodology and research methods are discussed.

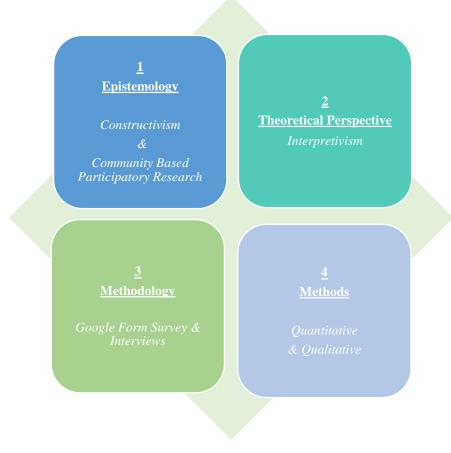


Chapter Three: Methodology

3.1 Introduction

This chapter will discuss the research process undertaken. The reader will be provided with an understanding of the epistemological and theoretical perspectives underpinning the study. The Community Based Participatory Research paradigm i.e., UCC CARL initiative is outlined. Furthermore, the research methodology used will be introduced and discussed. 48 survey responses were collected whilst additionally, 30 adoptees chose to participate in follow-up interviews of which 6 adoptees were selected for interview on a first come first serve basis. Finally, ethical considerations are analysed, the reflexive positioning of the researcher is discussed, and the challenges as well as limitations that arose during the research process are addressed.





(Diagram adapted from Crotty, 1998)

3.2 Epistemology

Grix (2002) states that epistemology "*is concerned with the theory of knowledge*" (p.177). In this dissertation, the question arose as to whether the experience of DNA testing for participants is uniform or varied? For instance, Crotty (1998) makes reference to objectivism, which looks at knowledge as a separate entity from "the operation of consciousness" (p.17). On the other hand, Onwuegbuzie et al (2009), ascertained that multiple subjectivist accounts are required to develop a rich understanding of a phenomena or issue, wherein the "knower" is not viewed as distinct from the "known" in effect (p.122).

Therefore, social constructivism is an appropriate epistemology for this dissertation rather than objectivism, as for instance, it supports the view that "meaning is not discovered but constructed" (Crotty, 1998, p.17). Social constructivism believes that learning takes place in the context of social interaction. It is of the opinion that things do not exist in the absence of human society (Teater, 2015). The purpose of this study is to explore adoptees' individual experiences of DNA testing. Accordingly, adoptees' experiences in this case are determined to be different, rather than uniform. Applying a social constructivist stance, the focus is on adoptees' perspectives and "the meaning making activity of the individual mind" (Crotty, 1998).

3.3 Theoretical Perspective

Carey (2009) suggests that the theoretical perspective is the philosophical stance informing the research topics methodology. Bryman (2016) further asserts that the theoretical perspective is imperative in the research process as *"it provides a framework within which social phenomena can be understood and the research findings can be interpreted"* (p.18). With regards to this dissertation, an interpretivist stance was implemented. Interpretivism indicates that knowledge and understanding are derived from the lived experience of others within the social world (Onwuegbuzie et al, 2016). Hence, this dissertation aims to *"understand the opinions, emotional responses and attitudes articulated"* of adoptees (Carey, 2009, p.53).

This approach echoes the core research aim of this dissertation, which is to explore DNA testing from an adoptee perspective. In doing so, I consider how psychosocial approaches aid my knowledge of the topic and align with social work theories. The psychosocial is concerned with the social and emotional elements at play in a person's life (Howe, 1998). Therefore, I applied theories of human growth and development to this dissertation. For instance, I believe that

systems theory can be applied to this issue as change in adoption legislation at a macro level is long awaited. Moreover, attachment theory, life course and human lifespan theory provide further grounding for this research topic within a theoretical framework.

3.4 Community Based Participatory Research (CBPR)

According to Bates & Burns (2012), Community Based Participatory Research (CBPR) is research that is generated by the community. Essentially, it is research conducted with and for a community organisation wherein the student researcher, academic supervisor, and community partner work in collaboration (McIIrath et al., 2014). In terms of this dissertation, the participatory approach applied aligns with the principles of the Community Academic Research Links (CARL) project initiative. This ensured that adult adoptees were "actively involved" in the research process as their perspectives were a central feature (Carey, 2013, p.118). The research aims, objectives and questions set out in 'Chapter One', were devised through regular consultation with the community organisation differs and is subject to change. With respect to this dissertation, I believe that the positive relationship formed with the community organisation enhanced and further contributed to the research process. Throughout the course of the research, I was provided with opportunities "to work on live research questions in a real-life context" (Bates & Burns, 2012, p.4).

3.5 Research Methodology

The methodological paradigm refers to "*the logic, potentialities and limitations of research methods*" (Grix, 2002, p.5). This model links the aforementioned epistemological positioning, theoretical perspective and participatory approach applied. Additionally, these elements contribute to the selection of an appropriate research method (Crotty, 1998, p.15). Regarding this dissertation, primary research which bestows responsibility upon the researcher in terms of data collection and analysis was selected. Hence, a mixed method i.e., quantitative, and qualitative methodological approach was implemented. This consisted of a questionnaire using Google Form Survey software and online interviews over Microsoft Teams. Onwuegbuzie, Johnson & Collins (2009) state that researchers guided by constructivism navigate towards a qualitative methodological approach. Whereas the participatory approach encompasses all methods.

As stated previously, this dissertation focused specifically on the findings generated from the questionnaire. According to Onwuegbuzie, Johnson & Collins (2009), "a parallel mixed analysis" involves separate interpretation and presentation of the quantitative and qualitative data (p.129). Given this, a mixed methods approach was implemented through use of the questionnaire and interviews. Moreover, constructivists suggest that quantitative methods can present a generalised view of data which is primarily focused on statistical analysis. However, the use of "descriptive statistics" can attribute greater meaning to quantitative analysis (Onwuegbuzie, Johnson & Collins, 2009, p. 125). Therefore, to address this and ensure that adoptees experiences of DNA testing could be effectively interpreted from a constructivist stance, the questionnaire designed allowed for both closed and open questions to gather a variety of quantitative and qualitative responses. This also enabled participants to provide in depth responses throughout the questionnaire.

Through discussion with the community partner and academic supervisor, a questionnaire was chosen as the primary method in order to account for the sensitivity of the topic. As a result, my community partner identified that a questionnaire which *Aitheantas-Adoptee Identity Rights,* have used before could provide initial feedback on the topic. Thereafter, to allow for further qualitative analysis, the option of follow up interviews was provided. This was to ensure that participants were given the opportunity to contribute within their own boundaries.

3.6 Research Methods

Grix (2002) asserts that research methods "should be seen as free from ontological and epistemological assumptions, and the choice of which to use should be guided by research questions" (p. 180).

3.7 Sampling and Data Collection

3.7.1 Sampling

Bryman (2012) refers to sampling as choosing participants that align with the research questions devised at the outset (*See 'Chapter One'*). Primary research methods were utilised in this dissertation, whereby a questionnaire was generated, and semi-structured interviews were conducted. Through my community partner *Aitheantas- Adoptee Identity Rights*, I was provided with access to a sample group of participants for data collection and analysis. I

worked closely with my community partner to devise the questionnaire and ensure that the language of the questionnaire and interview schedules was ethically appropriate and sensitive.

My community partner facilitated distribution of the questionnaire which was shared amongst a closed *Aitheantas* Facebook group. The questionnaire consisted of 9 open and closed questions enabling quantitative and qualitative data collection through check box questions and additional comment boxes. With consideration as to the remit of this dissertation and research aim, the inclusion criteria applied to adoptees over 18 years of age, based in Ireland who engaged in DNA Genealogy Testing for adoption tracing purposes.

3.7.2 Data Collection

I provided *Aitheantas-Adoptee Identity Rights* with a copy of the Google Form link which was distributed on the 12th of February 2021. Firstly, adoptees were invited to read the information leaflet which outlined the rationale for this dissertation. Thereafter, the consent form enabled adoptees to actively participate in the research process. Overall, 48 responses were collected. The questionnaire was closed on the 15th of February 2021 due to the scope of the dissertation and subsequent interviews. At the end of the survey, participants were asked to indicate whether they would like to discuss the research further through semi-structured interviews. 30 participants expressed interest in this and provided their email addresses of which 6 were interviewed on a first come, first serve basis in accordance with MSW Research Ethics.

3.8 Data Analysis

Using Google Forms software, I analysed the quantitative data collected from the questionnaire. In terms of analysing the quantitative data, I implemented univariate analysis (Onwuegbuzie, Johnson & Collins, 2009, p. 125). More specifically, this includes interpretation of quantitative data "one variable at a time" (Bryman, 2012, p.337). Rather than analysing the data through bivariate analysis wherein correlations are drawn between variables, I then chose to present the qualitative responses separately. Moreover, I believe that the quantitative data generated provided a context for the qualitative results which were presented through thematic analysis. According to Braun & Clarke (2006), "thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data" (p.79). I identified themes pertaining to the questionnaire by familiarising myself with the qualitative responses and

compile a list of themes in accordance with the research objectives and questions. Three themes were examined and presented in conjunction with the literature cited in '*Chapter Two*' pertaining to DNA testing (Baptista, et al., 2016). With regards the interview findings, I also implemented the above method of thematic analysis.

3.9 Ethical Considerations

According to Carey (2009) researchers are required to admit "*practical and moral responsibility for their work*" (p.12). The ethical approval process for this dissertation consisted of two applications to the UCC MSW Research Ethics Committee for approval. Firstly, I submitted an application for ethical approval on the 11th of December 2020 which was subject to deferral. Additionally, a revised application was granted ethical approval on the 1st of February 2021. This decision identified some additional changes to be included which were subsequently approved by my academic supervisor (*See Appendix-A*).

The following table provides a brief overview of the most significant areas requiring further ethical consideration prior to data collection:

Research Aims and Objectives- Language

The committee recommended revision of the language used pertaining to my research questions and objectives. Initially I referred to the sample group as 'participants' however the suggestion to change this to 'adult adoptees' ensured my target audience was clearly outlined.

Additionally, the committee suggested that the use of DNA testing for tracing biological relatives needed to be stated explicitly. For instance, DNA testing is not exclusively for adoption tracing. A study conducted by Cai et al (2020) reiterated that the term DNA testing can be mistaken for *'genetic testing'* which is offered by healthcare providers (p.468).

The committee advised that the research question relating to social media could be revised. This was a valuable suggestion which ensured the research question was focused and clearly associated with adoption tracing methods.

Finally, the recommendation to include a research question relating to the role of adoption social work in search and reunion was suggested. This was a positive addition to the dissertation as it emerged that several participants had previously engaged with social work.

Inclusion/Exclusion Criteria

As per the recommendation, the target audience stated that participants needed to be adult adoptees over 18 years of age who specifically used DNA testing for tracing biological relatives. This ensured that the research study remained focused and considerate as to the scale and word count.

Data Collection and Storage

Initially I considered conducting both phone and video interviews. However, Microsoft Teams is advantageous as it has a recording feature and the ability to store data automatically. Given this, I decided to limit the data collection to MS Teams which proved to be efficient and worked well for participants.

Additionally, I revised the information sheets and consent forms in conjunction with the SREC forms available and explicitly stated details of the HSE National Counselling Service and my CARL partner. With regards the interviews conducted, I also added an introductory question to the interview schedule i.e. *"How did you feel about participating in the questionnaire?"* in accordance with the MSW Ethics Committee.

As a researcher, I recognise the importance of ethical considerations. With regards to this dissertation, I considered at length the emotional impact that this study could have for adoptees. Although this dissertation focused on the process of DNA testing, it was essential to acknowledge that family history is a sensitive topic for participants. I discussed this with both my academic supervisor and CARL partner to ensure that support was available to participants should they feel distressed or upset at any point whilst completing the questionnaire and interviews. Although the ethical approval process was challenging at times, it ensured that the research project was ethically sensitive and that participants were supported throughout.

3.10 Researcher Reflexivity

As Sword (1999) outlines, it is important to acknowledge that research cannot be declared as free from the imprint as such of the researcher in terms of assumptions and bias. Whereas Ritchie et al (2014) refer to the concept of empathic neutrality wherein the researcher states their reflexive positioning and through this awareness, tries to contain it during the research process. This concept is associated with the epistemological perspective i.e., social constructivism which underpins this dissertation. I believe that the reflective journal I engaged with throughout the research process enabled me to situate myself within "*a middle ground*"

in terms of empathic neutrality (Quinn Patton, 2015, p. 457). With regards my position as the researcher, I also have no prior affiliation with the community partner or this research topic.

3.11 Challenges and Limitations

Considering the exceptional response received from the research participants, a significant limitation was the overall word count and time constraints. It is possible that the publication of the Commission of Investigations Report (2021), provided this topic with greater media attention. As such, I conducted interviews with the first 6 participants in accordance with MSW Research Ethics. As a result, it is with regret that more adoptees could not have been interviewed. However, due to the factors mentioned, it was important to recognise the narrow scope of this dissertation as it is a minor piece of research. A significant challenge on my part as a researcher was the large amount of data collected and the time frame for submission of this dissertation. On reflection, I feel that the project may have been conducted in partnership with another research student, due to the vast amount of data gathered. Although, this was not something I could have anticipated at the outset and the significant data received warrants further studies of this type.

I am of the view that the design of the questionnaire generated could have been improved upon. For instance, the addition of Likert scale questions and checkbox options could have assisted my data analysis. Moreover, it would be interesting to explore whether adoptees engaged with social work services before or after using DNA testing. Although, due to the phrasing of this question, this was not possible to interpret. Overall, I believe that I worked to the best of my ability to produce a considerate and substantial piece of research albeit the limitations and challenges discussed.

3.12 Conclusion

The chapter set out to examine the research process including the epistemology, theoretical perspective, methodology and research methods involved. Additionally, the ethical approval process was discussed, and ethical considerations were presented. The reflexive positioning of the researcher was also examined. Thus, the challenges and limitations that arose during the research process were outlined. Given this, the next chapter will provide the reader with an analysis and discussion of the primary research findings gathered.



Chapter Four: Findings

4.1 Introduction

This chapter presents the findings collected from the questionnaire and semi-structured interviews conducted. Employing a mixed methods approach encouraged a comprehensive exploration of adult adoptees personal experiences of utilising DNA testing. The questionnaire data is analysed and discussed primarily in accordance with the literature cited in *'Chapter Two'*. The quantitative findings will first be presented to the reader. Thereafter, the qualitative findings collected in response to the open-ended questions included in the questionnaire are addressed. Thematic analysis is utilised to identify three main qualitative themes.

4.2 Quantitative Data Findings

Participants were first asked to identify how they first became aware of DNA testing as a methodology for adoption tracing. The most common source of information on DNA testing for this purpose was social media. Almost half of the questionnaire respondents (48%; n=23) reported social media, primarily the platform Facebook, was how they first acknowledged DNA testing as a viable option for adoption tracing. TV/ Radio was identified as the second most significant source of information on DNA testing, indicated by 27% of participants. Specifically, family history programmes such as "*Adoption Stories*" (P.1) were frequently mentioned.

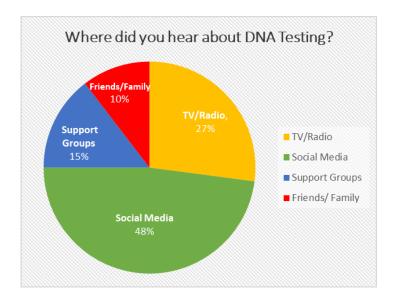
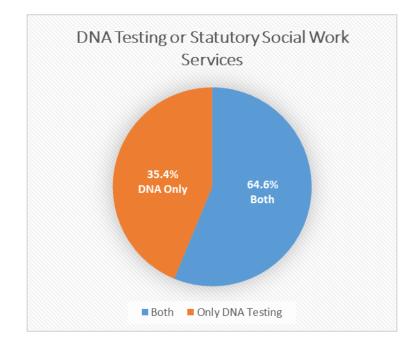


Figure 1- Awareness of DNA testing

Figure 2- Methods of Adoption Tracing



Inclusion criteria for this questionnaire stated that participants were required to have used DNA testing for tracing biological relatives. This question aimed to assess if the participants had only used DNA testing or had also used alternative methods to DNA testing for this purpose. The findings reported that 64.6% (n=31) of participants engaged with both DNA testing and adoption social work services. In contrast, 35.4% (n=17) of participants were found to have exclusively used DNA for adoption tracing. With regards to specific alternatives to DNA testing, participants reported they had used resources such as the "General Registration Office (GRO)", "National Adoption Contact Preference Register", "Religious bodies" and "Rip.ie". Whereas participant (5) noted the use of "internet research" as an additional tool to DNA testing.

Due to the short response nature of this questionnaire, it is not possible to decipher whether the 35.4% of participants that used multiple forms of adoption tracing had used DNA tracing prior to social work services or vice versa. Considering that 64.6% of participants utilised both DNA and adoption social work services, questions arise in relation to the motives of adoptees in deciding to use more than one method for tracing. It is possible that participants opted for DNA testing as an additional method to adoption social work services as a means of accessing more information than they had previously received in their search and reunion experience. This would be an interesting follow up to this study as it would allow for a direct comparison

of the efficacy of novel methods of tracing, such as DNA testing and more traditional ones like statutory social services. Lee et al (2020) reported that adult adoptees in the United States (n=117) have migrated from traditional methods of tracing as they are less efficient due to the length of time incurred in the search and reunion process. The findings reported in this dissertation are in agreement with Lee et al (2020), wherein adoptees selected similar "*steps taken to search for biological family*" (p.5).

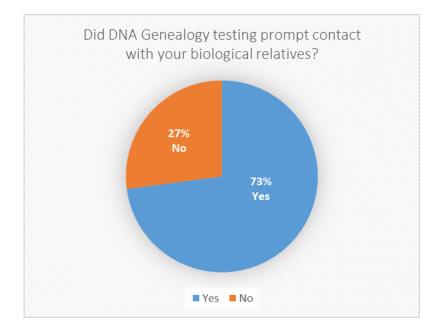


Figure 3- Outcome of DNA Testing Results

73% of participants (n=35), adoptees matched with their biological family. However, the efficacy of these matches differed for participants. For instance, one participant mentioned that the "closest willing to engage is a 3^{rd} or 5^{th} cousin who can't help" (P. 23). Furthermore, another participant who failed to connect with their matches, remained optimistic in the absence of a response:

A lot never replied, including my highest match on 23andme, a possible first cousin. Another very high 1st cousin or low possibly half-sister ran from My Heritage. Either she blocked me or deleted her account. I hope one day she will connect (P. 35).

27% (n=13) of participants reported that DNA testing did not bring about matches or connections with their biological family. Once again, some adoptees remained optimistic that the results could still yield a match. Indeed, one participant commented that it has *"not yet prompted contact but it may do"* (P.5). The 27% of participants that failed to record any matches brings about an inherent limitation of DNA testing for biological tracing. This

constraint is due to the fact that in order to generate a match, adoptees relatives are required to have also used DNA testing. This limitation is counteracted somewhat by the fact that any member of an adoptees extended family can prompt a match. Therefore, this avoids the requirement for one's birth parents to have also used DNA testing, for instance.

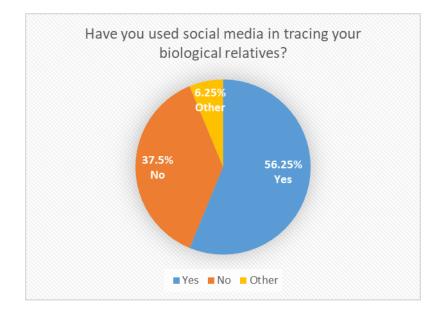


Figure 4- Tracing Biological Relatives with social media

The majority of participants i.e., 56.25% (n=27) were found to have utilised social media in conjunction with the DNA testing process. The emergence of social media platforms has prompted vast improvements in the ease of communicating and connecting with a worldwide audience. This provided one participant with opportunity to identify with the characteristics of another biological relative:

Facebook confirmed other connections and gave me the first person that I felt I looked like (P.35).

Furthermore, another participant commented that social media acted as the medium for reunion:

We used it to connect after initial contact had been made via the DNA platform (P.1). 37.5% (n=18) of participants reported that they had used social media to trace their biological relatives. 6.25% (n=3) of participants were included as 'other', because: they had *"not yet"* (P. 10) used social media, had *"limited information available"* to conduct a search through social media (P.27) and *"tried but had no luck"* (P.32).

The findings reported in this section address the third research question of this dissertation, which sought to evaluate the impact of social media in the tracing process. The literature outlined in '*Chapter Two*' noted that the emergence of social media and technology has positively impacted adoption practice. More specifically, Whitesel & Howard (2013) found that "*internet use often complemented other search processes*" (p. 20). With regards to this dissertation, participants further expanded on their perception of using social media in the search process which is presented thematically.

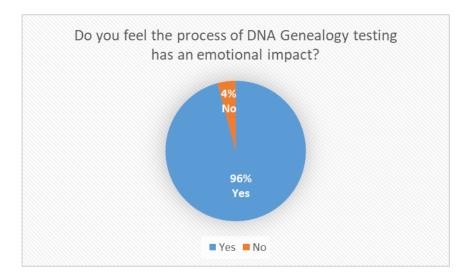
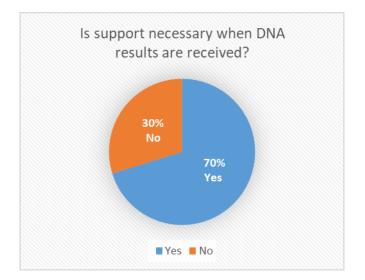


Figure 5- Emotional Impact

It is essential to recognise that the story and experience of participants upon using DNA testing is unique for each individual. This point is strengthened by 96% (n=46) of participants indicating that the process of DNA testing had an emotional impact on them. Some participants noted feeling a lack of control, anxiety, stress, and emotional vulnerability. Such emotions did not necessarily lead to negative implications for the adoptees interviewed in this dissertation. For instance, one participant noted that the process had evoked emotions *"in a positive way"* (P.10). This question yielded several qualitative responses and is illustrated within the thematic analysis section in conjunction with participant's views on developing a support system. Regarding this dissertation, these findings are in agreement with several studies which recognise the emotional vulnerability of seeking ancestral information. For instance, Allyse et al (2018) outline the vulnerable position that some adoptees can be in depending on results.





70% of the participants (n=33) reported that support is important when DNA results are received. In contrast, 30% (n=14) of participants noted that support is not relevant when using this method of adoption tracing. Participants commented on the adequacy of support services in the Irish context and provided recommendations where relevant. Considering these results, the importance of recognising adoptees as a service user group is crucial for effective and quality service delivery.

As illustrated in the above section, search and reunion is a complex process and one that demands a multi-faceted approach. The research above indicates that successful search and reunion calls for a variety of methods including DNA testing, adoption social work services and social media. In addition to this, the research emphasises the emotional impact and the complexity of the process for participants. This in turn, highlights the need for an improvement of search and reunion professional support in the Irish context. Moreover, the difficulty adoptees face with interpreting DNA results has been mentioned by previous studies (Allyse et at, 2018).

4.3 Qualitative Findings: Thematic Analysis

4.3.1 Theme One: DNA testing in the Search for Connection

The data gathered from the participants (n=48) links to the second research question presented in this dissertation i.e. *What reason can be identified as contributing factors for using DNA Genealogy testing?* Overall, 85% of participants (n= 41) stated the principal reason for pursuing DNA testing was "to try and find biological relatives" (P. 27). Several participants noted "*identity*" as a motivating factor. According to one participant:

I did so because, as an adoptee, I never felt that I belonged in the family I was adopted by. I really needed to find out my true identity (P.17).

Additionally, some participants noted DNA testing "*as a last resort*" (P.31) to statutory services or traditional methods of adoption tracing (Lee et al, 2020). One participant noted the ability to be in control of the tracing process:

I wanted a 'quick hit'. *I* had researched the other methods and heard how difficult it was to get information (P.23).

Some participants noted a lack of records due to their adoption being *"illegally registered"* as a reason for DNA testing (P. 25). Although curiosity about *"ethnicity"* (P.10) and about *"where I am from"* (P. 43) was noted as a factor for 8% of participants:

I can scientifically prove who I am now, but my legal identity documents are inaccurate and incomplete (P.17).

On the other hand, 6% of participants stated that lack of medical information initially prompted use of DNA testing. One participant noted their motivation was family orientated:

To find out information for my medical health and my children (P.36).

4.3.2 Discussion

The desire to learn and discover information ascertaining to family history is a recurrent theme in my findings. My findings are in line with research conducted by Lee et al (2020) which reported that (83%) of adoptees selected finding a biological family as central. With regards to this dissertation, lack of access to birth information and the falsification of records resulted in DNA testing as the only option to find information (May et al, 2016). My findings contrast with research by Baptista et al (2016) who recorded that health information was the main aim of many participants (84%) use of DNA testing. Although Baptista et al (2016) pointed out that *ancestry*" was nonetheless significant for adoptees (p. 926).

Interestingly, participant (28) above referred to DNA as perhaps a routine stage of the overall adoption tracing process. This could suggest that DNA testing is a part of the standard tracing process essentially for those tracing biological families. Is this a model of adoption tracing which needs greater attention? More recently, the Commission of Investigations Report (2021) noted the impact of DNA technology on the search and reunion process.

As discussed in the literature review, the prospect of answering questions of personal identity through DNA results is relevant for some participants such as participant (17) above. It could be argued that DNA testing offers an answer to the biological question of *'who am I'*. Although in terms of identity formation this process may not provide an in-depth answer. For instance, Grotevant (1987) argues that identity is a fluid process. With regards to adoptees, being able to recognize the self in another often for the first time can be deeply personal (Corder, 2012). The deeper issues of adoptees' sense of who they are in relation to others is due further analysis and it is hoped that the additional report due to be compiled following this dissertation will address this.

4.4 Theme Two: Adoptee's Assessment of DNA Testing

Participants offered a range of intriguing answers when asked to provide advantages and disadvantages for DNA testing as a method for tracing. While some participants had unique examples of advantages and disadvantages to this question, a number of common answers also arose. For instance, 38% of participants (n=19) responded solely with advantages, 14% (n=7) responded with only disadvantages and 48% (n=23) gave both advantages and disadvantages.

4.4.1 Advantages of DNA testing for tracing

In terms of advantages of DNA testing, a number of participants agreed that this method of adoption tracing is *"accurate"* (P.21), *"quicker"*, *"honest"* and more *"fact based"* than traditional methods of tracing heritage, such as working with social workers (P.2). One participant noted that:

Advantages are not having to deal with social workers, not relying on scraps of info, and being in charge of your own search (P. 18).

According to Participant (25) "DNA does not lie". Additionally, Participant (44) commented that "People lie, DNA does not!". Furthermore, participants indicated that the reliability of DNA testing helps to "fill the gaps in my own human history/ancestry/genealogy" and highlight potential diseases in their family history (P.15). Participants also agreed that DNA testing is an advantageous tool to consider when they were "not getting any answers" (P.42). The anonymity of DNA testing was also highlighted by one participant who stated, "it's online so somewhat anonymous depending on the control and info we share" (P.3).

Participants who used social media (n=27) were asked to indicate whether they believed social media provided greater access to information concerning biological relatives. The majority of participants (88%) (n=42) in this case stated that they viewed social media as a helpful tool allowing them *"to perhaps see relatives"* (P.8). As such, participant (46) commented that social media is essentially *"all part of the process"*. Whereas participant (15) commented that, *"my father's name is too common"*.

Although, one participant outlined that social media proves useful but noted that:

Social media helps, but it's not as important as DNA testing (P.17).

4.4.2 Criticism

Participants revealed several disadvantages of DNA testing for tracing. A common disadvantage highlighted by participants occurred when their biological relatives were not willing to be contacted and rejected adoptees approaches of reaching out. This experience was referred to as *"so frustrating and upsetting"* (P. 34).

Indeed, not establishing positive and active relationships with birth relatives was identified by participants as a painful and disappointing experience encountered with using DNA testing and tracing. This problem is exacerbated as there is currently no *"controlled way of making contact"* (P. 32). Thus, a further burden is placed upon the adoptee as one participant noted that *"you do this alone, and you have no guidance or support on how to deal with the results"* (P.20).

Concerns were also raised about the potential risks and limitations of companies providing DNA testing. These included, the financial expense of the service, the significant waiting time for results, a lack of professional support to *"decipher results and info"* (P. 15) and confidentiality concerns around *"DNA being open to being abused by companies"* (P.45). Another limitation of the DNA testing database was mentioned by some participants as the

family member you are trying to find needs to have also used the service, as indicated previously in the quantitative data outlined, "*the disadvantage I have come up against is that I found no close relatives*" (P. 23).

4.4.3 Discussion

The findings outlined above are in accordance with research from Baptista et al (2016), which also explored the value of DNA testing. Baptista et al (2016) reported that DNA testing is an advantageous and crucial method of tracing for adoptees. Interestingly, participants in this dissertation noted that DNA testing provided them with greater autonomy and anonymity. Similarly, Lee et al (2020) reported that this method enabled adoptees to obtain family health history indirectly for instance without initiating contact prematurely with biological relatives. Whitesel & Howard (2013) indicated that anonymity "gave both birth family members and adopted people some space to decide how they wanted to proceed" (p.20). In contrast, some participants critiqued the efficacy of DNA results. Participants also noted their disappointment with a lack of close matches and complexity of interpreting results. The lack of professional help when using private tracing methods, such as DNA testing or internet searches, has been previously reported to leave adoptees in a vulnerable position (McCaughren & Lovett, 2014). Interestingly, concerns relating to data usage and privacy of sending DNA to private companies was not a major issue raised in this dissertation. These findings contrast with research from Strong et al (2017) and Lee et al (2020).

It is possible that the history of access to birth information for those impacted by adoption in the Irish context aligns with Baptista et al (2016) suggestion. Baptista et al (2016) suggested that adoptees are not overly concerned with data usage as they are advocating for open access to their information. Moreover, literature outlined in *'Chapter Two'* noted that the discourse around social media tends to be saturated by risk (Shier, 2019). It was intriguing to see several participants highlight the benefits of social media which coincides with previous studies that reported the positive implications of social media for adoption practice (O'Brien, 2013). With regards to this dissertation, it is evident that social media provides participants with greater access to relatives. Whitesel & Howard (2013) previously identified the *"value of seeing pictures of family members online"* for adoptees as beneficial (p. 20). Regarding this dissertation, one participant noted that a search on Facebook for instance could yield thousands of results. Similarly, Whitesel & Howard (2013) reported that *"some adoptees (9%) also*

experienced frustration when birth parents' surnames were very common" (p. 17). Overall, this research identifies DNA testing along with social media as valuable tools in the search and reunion process. However, it also emphasises the need for these approaches to be more controlled and regulated to offset the above criticisms of the same.

4.5 Theme Three: 'Support is there but it isn't visible'- Adoptee's Proposals

The emotional impact of obtaining tracing results was a significant theme which arose upon interpretation of the qualitative data. According to one participant:

I am finding this journey way more emotional than I ever expected (P. 35).

Whereas another participant acknowledges the impact of adoption more generally wherein:

Additionally, some participants referred to the vulnerable position that can arise once DNA results are obtained. One participant emphasised the importance of support:

To help you through the emotional trauma which you do not expect but arrives like a thief in the night (p. 36).

Moreover, (70%) of participants noted that support is necessary in terms of the DNA process itself. Several participants referred to the need for more general adoption support service also.

Participants commonly noted friends and family members as a method of support. "You need support of family and friends for sure" (P. 41). According to several participants, the availability of online adoptee support groups over social media is a beneficial resource to adoptees:

Also, adoption support Facebook pages are great, they 'get it'... (P. 35).

I am part of Facebook groups who were set up to support adoptees from certain institutions and who are tracing with DNA. I don't really contribute as I don't often feel able, but I have felt a sense of support there (P.23).

Participants noted the lack of support services in Ireland as they made reference to long waiting lists within adoption agencies, lack of "*specialised supports*" (P.15) for adoptees and the financial costs associated with seeking private counselling services. One participant commented that:

Everything in relation (pun intended) to the whole area of relinquishment, adoption, searching, support, DNA testing and Adoptee rights in Ireland, can and should be improved upon (P.19).

Participants also noted the lack of support in relation to analysing DNA results as part of the adoption tracing process. One adoptee noted that "*local phone numbers for counselling services should be with each Kit*" (P.8). Several participants made reference to the role of the government to improve adoptee support services both generally and in terms of DNA testing.

Well information on how to actually search, how to communicate to birth family members is limited or non-existing when you are not engaged with social workers and are searching alone. There is no support at all for DNA testing. There isn't even option for adoptees to have access to genetic medical testing which could save lives if adoptees have no medical history at all (P.20).

Other participants noted that assistance with gathering DNA results should be provided for as one participant commented:

A genealogist should also be provided as part of the 'package' who can help trawl through the reams of data, complex family trees & obscure community records (P.15).

4.5.1 Perception of the Role of Social Work in Tracing

Participants who engaged with both DNA testing and Social Work Services (64%) outlined in the quantitative data above also commented on the of role adoption social work including, searching for adoptees biological relatives, initiating contact on behalf of both birth parents and adoptees and mediation: "*A social worker contacted me to intermediate contact between my birth mother and I*" (P. 32). Whereas one participant commented:

Major role, no information unless they decided to release it to you. I only used DNA when I was getting no help re social worker- they are more pro birth mother than the adoptee, you come last in the chain and are expected to be grateful and take what you get (P.36).

Another participant noted the significance of the Social Work role:

The Social Worker got in touch with my birth mother through a letter and went from there. I had a meeting with the social worker as well as counselling with her, she was extremely helpful (P.41).

Participants referred to issues of Information and Tracing (2016):

Laws and proposals come and go...decades come and go, but we as a vulnerable marginalised community have been accessing our information by ourselves, year after year. We can obtain our birth certs, we can find our first families, we can do DNA tests and we have the ability to get our answers (P.19).

Several participants' experience centred on the non-identifying information they received. They described Adoption Social Workers as, "*Gatekeepers to the information in my file*" (P.7), "*Obstructive*" (P.24), "*Of no help*" (P.29) and "*Fairly useless*" (P.48) whereas one participant commented:

My Adoption Agency Social Worker offered advice and was professional, *sensitive*, *and confidential*, *but not forthcoming with pertinent information* (P.19).

In this regard, participants referred to a "*difficulty with Social Work as a legacy issue*" (P.17) in terms of adoption. Another participant commented on the role of Social Work in conjunction with the DNA testing process and added that they have "*no role in DNA testing*" (P.14).

4.5.2 Discussion

The findings discussed in this dissertation indicate the varied experiences of adoptees engaging with statutory adoption services. Some participants made reference to the benefits of engaging with the mediation services provided by social work in the search and reunion process (Adoption Authority of Ireland, 2021). The primary data retrieved in the form of a questionnaire and interviews highlight the negative view towards social work as a profession and their role within the overall search and reunion process. On close review of these responses, it becomes evident to the reader that these views do not arise from a direct condemnation of the social work profession or the individuals working in Irish social work services. It can be argued that these responses more accurately derive from a frustration towards the wider societal systems in which search, and reunion takes place in Ireland today, namely the current adoption legislation and policy structures in place. It appears that on a wider societal level, the systems in place pertaining to *Information and Tracing (2016)* for members of the adoption triad are complex. The participants in this dissertation have referenced the impact of this and their voices indicate the need for systemic reform.

Moreover, participants referred to the past social attitudes pertaining to adoption, children and women and the larger discourse relating to Irish adoption as provided in *'Chapter Two'*. As Treacher and Katz (2002) note, *"the process of adoption involved much more than the 3 sides of the triangle"* (p.216). McCaughren & Lovett (2014) previously referred to Ireland's difficult history of adoption and the impact for those affected by adoption. As the systems theory

perspective suggests, the individual and their environment are viewed as interconnected (Mattaini & Meyer, 2002). As this is a sensitive subject for all members of the adoption triad, addressing these issues requires careful critical debate, which the Law Reform Commission (2000) have previously acknowledged. Childers (2017) and Allyse et al (2018) identified that the outcome of results could have an emotional impact for adoptees in some cases. One participant referred to similar research by May et al (2016) which acknowledged that adoptees' lack of health history can prove to be a disadvantage. Additionally, several studies pointed to the role that genetic counselling can play in this regard.

In Ireland, the Commission of Investigations Report (2021), acknowledged that "there can be problems for people who find very important information in this manner and who do not have any support system in place" regarding this method of tracing (p.28). Furthermore, participants in my dissertation acknowledged the benefits of online adoption support groups. It is evident that these support groups provide a positive avenue for adoptees. For instance, O'Brien (2013) previously pointed out the benefits of online forums and support groups. With regards to this dissertation, although each participant's story is different, an underlying theme is ever present, which reaffirms the lived experience of adoption and use of DNA testing for tracing biological families.

4.6 Conclusion

The primary data and discussion piece that follows as above, allows the reader to arrive at a conclusion of the need for reform for search and reunion practice in Ireland today. The need for a more comprehensive approach towards search and reunion in Ireland presents itself in the findings of this research. A call for reform of the current practice to include a more controlled and regulated use of all resources available to achieve successful tracing and reunion needs to be considered. The final chapter will further expand on the findings gathered and will offer recommendations, concluding thoughts, areas of future research and a reflection on the research process.



Chapter Five: Conclusion

5.1 Introduction

This chapter will provide the reader with a comprehensive overview of the research conducted. I will present a series of concluding thoughts based on the research aims and findings. A number of recommendations will then be offered based on the findings and literature previously discussed. Finally, areas for future research will be outlined followed by a reflection regarding my engagement with the CARL initiative and collaboration with *Aitheantas-Adoptee Identity Rights*.

5.2 Concluding Comments

This dissertation aimed to gain an insight as to adult adoptees use of DNA testing for tracing biological relatives and explore the significance of social media in the overall search and reunion process. This research provides an examination of current and traditional methods of adoption tracing as expressed by adoptees themselves. Essentially, I intended to gain a greater understanding of the search and reunion process in modern Ireland. Hence, I believe this research also offers possible solutions to some of the adoption issues modern Ireland faces.

The participants identified that DNA testing has emerged as an alternative method of search and reunion. It was found that this method of tracing biological families can yield quicker results for some adoptees in comparison to traditional methods. Although participants identified that this method is open to debate. While it is efficient, it may not in fact yield close familial matches or provide a direct route to birth information. Participants emphasised the need for assistance in some cases to interpret results, a point which has been raised by previous literature, cited in this dissertation. It was found that the psychosocial impact of DNA results was of great significance for participants who were on a journey of search and perhaps reunion. Given this, participants reported an absence of support available to adoptees, specifically those using DNA testing in Ireland.

Furthermore, numerous questions have arisen on my part throughout the research process, for instance, is this the commercialisation of adoption tracing? How confidential is closed adoption today? Is there a greater role for social work services? Whilst this dissertation cannot answer these questions, it identified the need for a more holistic approach to search and reunion policy and procedure in Ireland in accordance with systems theory, the question arises as to whether

this needs to be a general overhaul of adoption tracing and the search and reunion process to better support adult adoptees. Given this, perhaps the amalgamation of varying tracing services for locating biological families is necessary.

5.3 Recommendations

The following recommendations are shaped by the findings of this dissertation along with the literature relevant to the topic:

- The findings indicate that DNA testing proves to be a valuable resource in the search and reunion process. However, participants expressed that there is a need for an improved search and reunion service in Ireland. As such, a better regulated approach to support adoptees who use this method of adoption tracing is key. As participants have suggested, this could be achieved through the addition of genealogists to assist with interpretation of DNA results. Correspondingly, participants noted that DNA testing should be provided free of charge to adoptees.
- A recurring theme which arose in the research was a need for an improvement in emotional support for adoptees engaging in search and reunion. The findings indicated the value of online adoption support groups, as participants stated the power of validation gained from other adoptees. Additionally, participants reported that adoption tailored counselling services should be widely available. This would be an optional service and a means of restitution to those impacted (O'Rourke et al, 2018).
- I believe that there is an onus on the Irish state to reform the way in which adoption services are delivered. Given this, the matter of legislation pertaining to *Information and Tracing (2016)* is a long-standing issue that awaits a steadfast solution. As such, the Clann Project previously commented that:

The abuses committed in the past are perpetuated in the present due to the Irish State's denial of information rights to adopted people and natural parents (O' Rourke, et al., 2018, p.8).

As expressed by the participants who contributed to this dissertation, this matter affects birth parents, adoptees, and adoptive families.

 Additionally, I am of the view that there is a need or gap in service delivery which could be met by social work professionals. As such, a reform in adoption services pertaining to search and reunion could restore adoptees faith in the profession as a whole. This could include an integration or one stop service provider consisting of DNA testing, social work services and social media/online search resources perhaps. This would ensure both safe and effective service delivery to a vulnerable service user group within Irish society.

5.4 Future Research

- The data gathered from this dissertation will be available to *Aitheantas-Adoptee Identity Rights* for further analysis should the need arise. Additionally, this could be an opportunity for future CARL projects based on this research topic. As such, a comparative study examining whether adoptees used DNA testing before or after social work services could prove an interesting research topic.
- Moreover, further research could examine Irish adoptees' experiences of genetic testing and critically explore healthcare standards relating to adoptees who lack health history. Childers (2017) recommended that the field of genetic counselling could particularly benefit from increased studies on this topic. As this study consisted of a small sample size, a larger longitudinal study on the topic could also prove advantageous (Baptista et al, 2016).
- I will analyse the data gathered from the follow up interviews and present my findings at a later date in a subsequent report for publication. Due to the scope of this dissertation, an additional report will provide ample opportunity for in-depth analysis. Childers (2017) remarked that in relation to adoptees *"little qualitative insight is available for this population's experience"* (p.30).

5.5 Reflective Piece

When I started this research process, I could not have predicted the considerable response that I received to the online questionnaire and follow up interviews. Given the publication of the Commission of Investigations Report (2021) in January, this research topic was also afforded greater media attention. On reflection, I believe that this research could have been conducted as a group project. At times, analysing the findings felt overwhelming due to the considerable

data collected. Although, with the support of my college tutor and CARL partner this process became rather enjoyable.

In accordance with Covid-19 guidelines, I conducted interviews over the *UCC Supplied Version of Microsoft Teams Video*, following the online questionnaire. Initially, I was apprehensive about conducting online interviews due to the sensitivity of the topic. I considered how meeting participants would differ in terms of non-verbal communication for instance and of course the chance of technical difficulties was always possible. However, many of us have adapted to online communications platforms due to Covid-19. As a result, I believe that the online questionnaire and interviews proved advantages as participants were provided with greater accessibility.

I believe that I have further enhanced the research skills that I previously developed in my undergraduate social science degree. I have learned the value of proofreading, editing, and acquiring the guidance of a critical friend. I have also learned the importance of collaborative working through my engagement with both the research participants and CARL partner who made this research possible. I extend my gratitude to *Aitheantas-Adoptee Identity Rights* for providing me with the opportunity to sit and listen to the adoptees who participated. I am honoured to have partnered with this community group. As such, I hope that this dissertation proves to be a valuable piece of research for my CARL partner. Thus, going forward I will present the interview findings gathered by means of an additional report. In this regard, I aim to provide an in-depth thematic analysis and make a valuable contribution to my wider community both professionally and academically.

Bibliography

- Adoption. 2021. *Social Work*. [online] Available at: https://aai.gov.ie/en/who-we-are/social-work.html [Accessed 21 April 2021].
- Aitheantas-Adoptee Identity Rights. (2021). Retrieved 18 April 2021, from https://adopteerights.ie/.
- Al Tamimi, Y. (2018). Human Rights and the Excess of Identity. *Social & legal studies*, 27 (3), s. 283–298. doi:10.1177/0964663917722598.
- Allyse, M. A., Robinson, D. H., Ferber, M. J. & Sharp, R. R. (2018). Direct-to-Consumer Testing 2.0: Emerging Models of Direct-to-Consumer Genetic Testing. Mayo clinic proceedings. doi: 10.1016/j.mayocp.2017.11.001.
- Ancestry.com, (2021). *Privacy Statement* Retrieved 22 April 2021, from https://www.ancestry.com/cs/legal/privacystatement
- Baptista, N. M. et al. (2016). *Adopting genetics: motivations and outcomes of personal genomic testing in adult adoptees. Genetics in medicine.* doi: 10.1038/gim.2015.192
- Bates, C. and Burns, K. (2012) 'Community-engaged student research: online resources, real world impact', in Quinn, A. M., Bruen, C., Allen, M., Dundon, A. and Diggins, Y. (eds.), The Digital Learning Revolution in Ireland: Case Studies from the National Learning Resources Service, Cambridge, Cambridge Scholars Publishing.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3 (2), s. 77–101. doi:10.1191/1478088706qp0630a
- Bryman, A. (2016) Social Research Methods. 5th ed. Oxford; Oxford University Press.
- Cai, J., Kim, A. Y. & Lee, R. M. (2020). Psychological correlates of interest in genetic testing among Korean American adoptees and their parents. *Journal of genetic counselling*, 29 (3), s. 460–470. doi:10.1002/jgc4.1237
- Carey, M. (2009) *The Social Work Dissertation. Using Small Scale Qualitative Methodology.* Maidenhead; Open University Press.
- Casas KA. Adoptees' Pursuit of Genomic Testing to Fill Gaps in Family Health History and Reduce Healthcare Disparity. *NarratInqBioeth*. 2018;8(2):131-135. doi:10.1353/nib.2018.0050

- Childers, A. (2017). Adoptees' Experiences with Direct-to-Consumer Genetic Testing: Emotions, Satisfaction, and Motivating Factors. (Master's thesis). Retrieved from <u>https://scholarcommons.sc.edu/etd/4110</u>.
- Christie, A., Featherstone, B., Quin, S., & Walsh, T. (2015). *Social Work in Ireland: Changes and Continuities*: Palgrave Macmillan.
- Corder, K. (2012). Counselling Adult Adoptees. *The family journal*, 20 (4), s. 448–452. doi:10.1177/1066480712452088
- Counselling Service for Former Residents of Mother and Baby Homes HSE.ie. (2021). Retrieved 27 April 2021, from https://www.hse.ie/eng/services/list/4/mental-health-services/national-counselling-service/counselling-service-for-former-residents-of-mother-and-baby-homes/.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process.* Sage Publications.
- Erikson, E. H. (1950). Growth and crises of the" healthy personality.".
- Fursland, E. (2010) Facing Up to Facebook, London, BAAF.
- Geissinger, S (1984) 'Adoptive Parents Attitudes towards Open Birth Records', *Family Relations*, 33, pp. 579-585.
- Government of Ireland, (1952-1998) Adoption Act, Dublin, Dublin Stationery Office.
- Government of Ireland, (2010) Adoption Act, Dublin, Dublin Stationery Office.
- Government of Ireland, (2016) *Information and Tracing Bill*, Dublin, Dublin Stationery Office.
- Government of Ireland. Final Report of the Commission of Investigation into Mother and Baby Homes (2021) Dublin: Stationery Office.
- Grix, J. (2002). Introducing Students to the Generic Terminology of Social Research. *Politics*, 22 (3), s. 175–186. doi:10.1111/1467-9256.00173
- Grotevant, H. D. (1987). *Toward a process model of identity formation*. Journal of Adolescent Research, *2(3)*, 203-222.
- Howe, D. and Feast, J. (2000) Adoption Search and Reunion: The Long-term Experience of Adopted Adults, London, The Children's Society.
- Lee, H., Vogel, R. I., LeRoy, B., & Zierhut, H. A. (2020). Adult adoptees and their use of direct-to-consumer genetic testing: Searching for family, searching for health. Journal of Genetic Counseling, n/a(n/a). doi:10.1002/jgc4.1304

- Law Reform Commission. (2000). Adoption law: The case for reform /a report by the law society's Law Reform Committee. Retrieved from <u>http://hdl.handle.net/10147/46298</u>.
- Maeve O'Rourke, Claire McGettrick, Rod Baker, Raymond Hill et al., CLANN: Ireland's Unmarried Mothers and their Children: Gathering the Data: Principal Submission to the Commission of Investigation into Mother and Baby Homes. Dublin: Justice for Magdalene's Research, Adoption Rights Alliance, Hogan Lovells, 15 October 2018.
- May, T. et al. (2016). Does Lack of "Genetic-Relative Family Health History" Represent a Potentially Avoidable Health Disparity for Adoptees. The American journal of bioethics, 16 (12), s. 33–38. doi:10.1080/15265161.2016.1240255
- McCaughren, S. & Lovett, J. (2014). *Domestic adoption in Ireland: a shifting paradigm?* Adoption & fostering, *38* (3), s. 238–254. doi:10.1177/0308575914543233.
- McCaughren, S. & Ni Raghallaigh (2015), 'Adoption in Ireland: Exploring the Changing Context' in Social Work in Ireland: Changes & Continuities, (eds.) Christie, A. et al., London, Palgrave.
- Mcilrath, L. et al. (2014). Emerging Policy and Practices on Community-Based Research—Perspectives from the Island of Ireland (s. 101–116). doi:10.1057/9781137385284_8
- Newton Verrier, N. (1999) *The Primal Wound: Understanding the Adoption Child, Baltimore*, Gateway Press.
- O'Brien V. (2013) 'Social networking, adoption and search and reunion'. Irish Social Worker, Summer, 24-32.
- O'Brien, V. & Mitra, S. (2018) An Overview of Adoption Policy and Legislative Changes in Ireland 1952-2017, Dublin, The Adoption Authority of Ireland.
- O'Halloran, K., (1994). *Adoption in the two jurisdictions of Ireland: a comparative study*. Aldershot; Brookfield, USA: Avebury, c1994.
- O'Mahoney, C., Logue, F., O'Rourke, M., Gallen, J., Daly, E., Enright, M., Ring, S., McMahon, R. and Cahillane, L., 2021. Opinion on the application of the Irish Constitution and EU General Data Protection Regulation to the Adoption (Information and Tracing) Bill 2016 and the Government's 'Options for Consideration'. [online] Adoption.ie. Available at: http://adoption.ie/wp-

content/uploads/2019/11/OMahoney_Logue_ORourke-Opinion.pdf> [Accessed 17 April 2021].

- Onwuegbuzie, A. J., & Frels, R. (2016). Seven steps to a comprehensive literature review: A multimodal and cultural approach.
- Onwuegbuzie, A. J., Dickinson, W. B., Leech, N. L. & Zoran, A. G. (2009). A *Qualitative Framework for Collecting and Analysing Data in Focus Group Research*. International journal of qualitative methods, 8 (3), s. 1–21. doi:10.1177/160940690900800301
- Onwuegbuzie, A., Johnson, R., & Collins, K. (2009). *Call for mixed analysis: A philosophical framework for combining qualitative and quantitative approaches.* International Journal of Multiple Research Approaches, *3*, 114 139.
- Patton, M. (2018). Facilitating evaluation. SAGE Publications, Inc https://www.doi.org/10.4135/9781506347592
- Powell, F., Geoghegan, M., Scanlon, M., & Swirak, K. (2013). The Irish Charity Myth, Child Abuse and Human Rights: Contextualising the Ryan Report into Care Institutions. The British Journal of Social Work, 43(1), 7-23.
- Redmond, P, J., (2018). Adoption machine: the dark history of Ireland's mother and baby homes: the inside story of how Tuam 800 became a global scandal. Newbridge, Co. Kildare: Merrion Press.
- Regalado, A. (2019). More than 26 million people have taken an at-home ancestry test. Retrieved from MIT Technology Review website https:// www.technology review.com/s/61288 0/more-than-26-million-people-have-taken-an-at-home-ancestrytest/.
- Ritchie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. London: Sage Publications.
- Roberts, J. S. et al. (2017). Direct-to-Consumer Genetic Testing: User Motivations, Decision Making, and Perceived Utility of Results. Public health genomics. doi:10.1159/000455006.
- Shapin, S. (1991). "A Scholar and a Gentleman": The Problematic Identity of the Scientific Practitioner in Early Modern England. History of science, 29 (3), s. 279– 327. doi:10.1177/007327539102900303
- Strong, K. A., May, T., McCauley, M., Pean Kirschner, A. L., Jeruzal, J., Wilson, S. L., Zusevics, K. L., & Knight, C. (2017). *Adult adoptees' attitudes regarding the*

potential use of genetic information to fill the gap in their family health history. Adoption & fostering, 41(2), 159–169. https://doi.org/10.1177/0308575917704553

- Sword W. *Accounting for Presence of Self: Reflections on Doing Qualitative Research.* Qualitative Health Research. 1999;9(2):270-278. doi:10.1177/104973299129121839
- Teater, B. (2010). *An Introduction to Applying Social Work Theories and Methods*. Open University Press.
- Triseliotis, J., Shireman, J & Hundleby., M. (1997) Adoption: theory, policy, and practice.
- Whitesel, A. & Howard, J.A. (2013) Untangling the Web II, A Research Based Roadmap for Reform, USA, The Donaldson Adoption Institute, Available from: http://adoptioninstitute.org/wordpress/wp-content/uploads/2013/10/AR2013.pdf
 [Accessed: 21.04.21]

Appendix- A

Confirmation of Ethical Approval from University College Cork MSW Research Ethics Committee

2021-SS6206:Dissertation in Social Work 1 February 2021 at 17:01 \bigcirc \textcircled{O}_{-} Applicant: MSW2, 2020/2021 Committee Date: 1st February 2021 Tutor(s): Reference: 2020-4

Dear Denise

Thank you for your application to the MSW research ethics committee.

The committee has granted approval for your study. Thank you for making the identified changes. There are some additional changes flagged using track changes on the attached file. Please discuss with your tutor, but there is no need to resubmit to the committee.

We wish you the best of luck with your study. If you have questions, please contact your MSW tutor.

Best wishes,

On behalf of the MSW Research Ethics Committee



School of Applied Social Studies

RESEARCH ETHICS FORM

Introduction

In UCC, research ethics is the remit of the University Ethics Committee (UEC). There are three ethics subcommittees under the remit of UEC, one of which is the Social Research Ethics Committee (SREC). This committee (SREC) reviews research proposals submitted by university staff and research-based postgraduate students seeking ethical approval for social research (as distinct from clinical research or research involving animal experimentation). The work of SREC is strongly informed by the UCC Code of Research Conduct (2018).

UEC and SREC seek to ensure that supervisors and researchers are sufficiently supported to undertake research (which may involve human participants) to the highest possible standards and with due regard to the welfare of all concerned.

PLEASE NOTE:

<u>All undergraduate and taught postgraduate students</u> (i.e. BSocSc, BSW, BYCW, MSocSc, MSW, HDip) should discuss the ethical implications of what research they are proposing to do with their supervisors and <u>complete this research ethics form for their supervisor</u> prior to any research being conducted involving human subjects. This form should be included as an appendix in the submitted research report, in addition to copies of information sheets, consent forms used, and the research instruments (e.g. questionnaire, interview schedule). It is strongly advised that all students adhere to the guidance on ethical issues provided by their supervisors and consult with supervisors should unanticipated ethical issues arise. Students should ensure that all forms being used to recruit, inform, and gain the consent of research subjects as well as the research instruments (e.g. focus group interview schedule/ questionnaire) being used have been reviewed by supervisors prior to conducting any primary research/ fieldwork. Students should carefully abide by any ethical guidelines for their research provided by their course teams or in their course handbooks, as well as the UCC Code of Research Conduct in their research. See: <u>UCC Code of Research Conduct</u>

Should disagreements or difficulties arise in relation to ethical issues that cannot be resolved between supervisor and student or course team and student, the assistance of members of the School of Applied Social Studies Research and Ethics Committees can be sought (e.g. Elizabeth Kiely at <u>e.kiely@ucc.ie</u> and Orla O'Donovan at <u>o.odonovan@ucc.ie</u>).

PART A: Complete this check list and discuss <u>with</u> your supervisor

If your answer falls into any of the shaded boxes, please address each point later on in the form.

		YES	NO	N/A
1	Have you discussed your proposed research and your ethical review with your supervisor?	Х		
2	Do you consider that this project has significant ethical implications?		Х	
3	Will the main research procedures be outlined to potential research participants in advance, so that they are informed about what to expect?	Х		
4	Will research participation be voluntary?	Х		
5	Will informed consent be obtained in writing from research participants?	Х		
6	Will you tell research participants that they may withdraw from the research at any time and for any reason, and (where relevant) omit questionnaire items/ questions to which they do not wish to respond?	Х		
7	Will data be treated with full confidentiality/ anonymity (as appropriate) ¹ ?	Х		
8	Will data be securely held for a minimum period of ten years after the completion of a research project, in line with the University's <i>Code of Research Conduct</i> (2016)?	Х		
9	If results are published, will anonymity be maintained and participants not identified?	Х		
10	Will participants be debriefed at the end of their participation (i.e. will you give them a brief explanation of the study and address any concerns they may have after research participation)?	Х		
11	Will your project involve deliberately misleading participants in any way?		Х	
12	Will research participants include children/ young persons (under 18 years of age)?		Х	
13	If yes to question 12, is your research informed by the UCC <i>Child Safeguarding Statement</i> , which sets out the legal requirements under the <i>Children First Act 2018</i> : UCC Child Protection Policy 2018			Х
14	Will your project require you to carry out "relevant work" as defined in the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016? ²		Х	

¹ Researchers must ensure the confidentiality of data gathered in the course of the research (i.e. where that data is not already in the public domain). Where appropriate they must ensure privacy or anonymity of human participants. Researchers should not intrude into persons' lives beyond what is required for the purpose of the research.

² Relevant work constitutes any work or activity which is carried out by a person, a necessary and regular part of which consists mainly of the person having access to, or contact with, children or vulnerable adults.

15	Do you require official Garda Vetting through UCC before collecting data from children or vulnerable adults? Having Garda Vetting through another body is not sufficient; UCC Garda Vetting is required.		Х	
16	Will research participants include people with learning or communication difficulties?		Х	
17	Will research participants include patients/ service users/ clients?		Х	
18	Will research participants include people in custody?		Х	
19	Will research participants include people engaged in illegal activities (e.g. drug taking, illegal Internet behaviour, crime, etc.)?		Х	
20a	Is there a realistic risk of participants experiencing either physical or psychological distress due to research participation?	Х		
20b	Is there a realistic risk of you, as the researcher, experiencing either physical or psychological distress?		Х	
21	If yes to question 20a, has a proposed procedure for linking the participants to an appropriate support, including the name of a contact person, been given?	Х		
22	If yes to question 20b, has a proposed procedure/support structure been identified?	Х		
23	Are the research participants also students with whom you have some current/previous connection (class members, friends, tutor, etc.)?		Х	
24	Will research participants receive payment/ gifts/ vouchers/ etc. for participating in this study?		Х	
25	Are you accessing, collecting or analysing confidential agency documents or case files? If yes, please give details of compliance with the agency's policy on data protection and confidentiality below in your review.		Х	
26	If your research is conducted on the internet, does it involve human participants (e.g. through web surveys, social media, accessing or utilising data (information) generated by or about the participant/s; or involve observing human participants in their online interactions/behaviour)? If yes, please review and utilise the UCC policy for conducting Internet Research.	Х		

If you <u>did not tick</u> any shaded boxes proceed to Part B and complete the relevant form. If you <u>did tick shaded boxes</u> please proceed directly to Part C and complete the relevant form.**PART B: DESCRIPTION OF THE PROJECT**

Ethical review requires that you reflect and seek to anticipate ethical issues that may arise,

rather than reproduce copious text from existing research proposals into these boxes.

Entries should be concise and relevant to the point/ question.

A. Very brief description of your study (15-25 words max.)

[e.g. This is a narrative literature review (desk-based) examining group work interventions with young people on the theme of sexual health]

Text here

B. What is your study about? (Aim and Objectives / Key Research Questions) (100-150 words max.) Text here

C. Concise statement of *anticipated* ethical issues raised by your project. How do you intend to deal with them? For example, your research could be desk-based but may still involve sensitive/ controversial material (100-150 words max.). In relation to any kind of research with human subjects you need to address the issue of informed consent and how that will be addressed, safe data storage (see page 8 of this document) for the duration of the project and beyond and how you will safeguard the rights and welfare of research subjects. If research is being conducted with <u>any</u> human subjects, information leaflets, consent forms etc., which have supervisor oversight, should be routinely used.

Text here

D. Have you discussed ethical issues pertaining to your research and has your supervisor approved what you are proposing?

Text here

PART C: DESCRIPTION OF THE PROJECT

Ethical review requires that you reflect and seek to anticipate ethical issues that may arise,

rather than reproduce copious text from existing research proposals into these boxes.

Entries should be concise and relevant to the point/ question.

A. Very brief description of your study (15-25 words max.)

[i.e. This is a qualitative study of primary school teachers' attitudes towards religious teaching using focus groups to collect original data]

My study aims to respectfully highlight the voice of adult adoptees and their experiences of the use of DNA Genealogy testing whilst ensuring confidentiality.

B. What is your study about? (Please include your research objectives and research questions here. 200 words max.)

From my research to date, it is evident that there is a need for further research relating to the experience of adult adoptees who have participated in the DNA Genealogy testing process. I hope to examine adoptees' use of social media during the DNA Genealogy testing process. I will also explore whether psychosocial support would be useful for adoptees during the process. Overall, this research aims to examine the use of DNA genealogy testing from the perspective of adult adoptees.

Research objectives:

- 1. To provide a brief overview of adoption legislation, policy, and practice in Ireland.
- 2. To examine international research and studies pertaining to DNA Genealogy testing as a means of further reference.
- 3. To explore the method of DNA Genealogy testing used to trace family history by discussing the experience with a sample group of adult adoptees.
- 4. To understand the factors that contributed to adult adoptees' decision to use DNA Genealogy testing for tracing biological relatives.
- 5. To examine popular discourses in relation to adoptive practices in Ireland to better understand the world of adoptees further, in particular social media.
- 6. To identify a way to add a psychosocial support context to the DNA Genealogy testing process used by Irish adoptees.

Research Questions:

- What was the experience of adult adoptees using DNA Genealogy testing for adoption tracing in Ireland?
- 2. What reasons can be identified as contributing factors for using DNA Genealogy testing?
- 3. Was social media helpful for Irish adoptees as an additional means of tracing their biological relatives?
- 4. How could psychosocial support be established for adoptees participating in the DNA Genealogy testing process in Ireland? What is the role of social work in adoption tracing?

C. Brief description and justification of methods and measures to be used (attach questionnaire/ interview protocol/ focus group discussion guide etc.)

This research project is a CARL project in collaboration with my Community Partner- Aitheantas. After discussion with my tutor Brien from Aitheantas, it was determined that I will use an online survey (*UCC- supplied versions of Google Forms*) and semi-structured interviews (*UCCsupplied version of MS Teams*) to collect my data.

I will provide participants with the opportunity to complete the online Google Form survey via the *UCC-supplied version of Google Forms*. The option of participating in a semi-structured interview will also be provided to participants over the *UCC-supplied version of MS Teams*. This option will be an opportunity for

participants to discuss the topic further should they wish to do so. I have devised my survey and interview questions in conjunction with my CARL partner from Aitheantas. I am mindful of the sensitivity of this research topic and the impact this piece of work could have for members of Aitheantas. In this regard, I have worked closely with **New Proposed** to ensure my proposed research is respectful and considerate to the anticipated participants who will undertake my survey and interviews.

Online Survey Questions: UCC- supplied version of Google Forms

Introduction:

- I will build the information sheet and consent form into the start of the Google Form Survey.
- I will email the consent form for the interviews to participants who choose to engage in the interview.

Survey Questions:

- 1. Where did you hear about DNA Genealogy testing?
- 2. What methods have you used for tracing your biological relatives i.e., DNA Genealogy testing or statutory Social Work services?
- If you engaged with a social worker, what role did they play in this?
- 3. Why did you engage in DNA Genealogy testing?
- What are the advantages of this? Do you think there are disadvantages to this method of tracing biological relatives?
- 4. Did DNA Genealogy testing prompt contact with your biological relatives?
- 5. Have you used social media in tracing your biological relatives?
- If you have, do you believe it has provided you with greater access to information relating to your biological relatives?
- 6. Do you feel the process of DNA Genealogy testing has an emotional impact on adoptees?
- 7. Is support necessary when DNA results are received?
- If so, are these supports sufficient in Ireland, or can they be improved upon?
- 8. Do you have any recommendations for developing support services in relation to the DNA Genealogy process? Is there anything you would like to add before completing this survey?

Finally, I would like to invite you to discuss this research topic further through a one-to-one interview. This interview will be conducted over the *UCC-supplied version of Microsoft Teams*. Please indicate whether you would like to discuss the topic further:

Yes, I would like to engage in a one-to one interview

No, I would not like to engage in a one-to-one interview ------

Furthermore, if you have any suggestions about how this survey could be improved, please do not hesitate to contact the researcher via email

In the event that participation in this study may unintentionally cause some psychological distress, please do not hesitate to seek professional help should the need arise. Please see the HSE National Counselling Service

n from Aitheantas (087-xxxxxx) is also available

in this regard. Our designated person to offer informal support.

For any former residents of Mother and Baby Homes seeking counselling support, the HSE National Counselling Service (NCS) is available to provide a counselling service from Monday to Friday between 9.30 and 5pm:

https://www.hse.ie/eng/services/list/4/mental-health-services/national-counselling-service/counselling-service-for-former-residents-of-mother-and-baby-homes/

HSE REGION	AREA COVERED	TELEPHONE NO
CHO Area 1	Donegal, Sligo & Leitrim	1800 234 119
CHO Area 2	Galway, Mayo & Roscommon	1800 234 114
CHO Area 3	Limerick, Clare & North Tipperary	1800 234 115
CH Cork, Kerry	Cork & Kerry	1800 234 116
CHO Area 5	Waterford, Wexford, Kilkenny, Carlow & South Tipperary,	1800 234 118
CH East	South Dublin, South East Dublin & East Wicklow	1800 234 111
CH Dublin South, Kildare & West Wicklow	South West Dublin, Kildare & West Wicklow	1800 234 112
CHO Area 8	Midlands: Laois, Offaly, Longford & Westmeath	1800 234 113
CHO Area 1/8	Louth, Meath, Cavan & Monaghan	1800 234 117
CHO Area 9	Dublin North & Dublin North City	1800 234 110

Interview Questions:

- 1. Can you elaborate as to what made you decide to use DNA Genealogy testing?
- 2. Can you talk me through what it was like to do the DNA test? What was that like for you?
- 3. What were your feelings at the time of using the DNA test? What did you do with the results?
- 4. What support was available to you at the time? Who supported you when you received your results?
- What would have been more helpful at the time?

D. Participants (recruitment methods, number, age, gender, exclusion/ inclusion criteria, detail permissions to be sought/ secured already). Please ensure that your supervisor sees any relevant information sheets and consent forms, confidentiality agreements etc. that you intend to use with research participants. How will you ensure that research participants' rights and needs are looked after in the research process?

How will the survey link be circulated?

I will provide participants with all necessary information relating to the study which will allow informed consent to be obtained. As participation is voluntary, participants will be provided with the option to 'opt out' of the survey and or interviews.

<u>Survey</u>

In relation to how the survey link will be circulated. I have clarified with **Constant Sector**; my CARL partner that Aitheantas have a DNA support group on Facebook which is a closed group. All these people have an interest in the DNA aspect and the vast majority have already taken DNA tests. I will forward the link for my Google Form Survey to my CARL partner who will circulate it amongst this closed group.

Interviews

I have included a tick box option at the end of my survey for participants to engage in a one-to-one semistructured interview. This will ensure that I can select participants i.e., 5/6 for further discussion of my topic. I will then use my UCC email to arrange interviews over the *UCC supplied version of MS Teams*.

Inclusion criteria

As this research project is a CARL project, I will be working with participants provided by Aitheantas which consists of adults who were adopted. I will outline in my information sheets that the target audience is adults over 18 years of age, who have undertaken DNA Genealogy testing specifically for adoption tracing.

Exclusion criteria

As this research project is a minor dissertation (i.e., 10,000 words), I have chosen to exclude members from Aitheantas who have not engaged in DNA Genealogy testing for adoption tracing. I have consulted with my tutor in this regard and have thereby narrowed my target audience to generate results specific to my research aim.

How many participants does the student anticipate? How many survey responses?

It is difficult to determine the number of participants and survey responses that I will receive as Aitheantas have approx. 800 members. However, my survey will target those who have used DNA Genealogy testing to narrow the participants. At this point, the approximate number of responses is unavailable to me.

How many interviews does the researcher anticipate conducting?

I will limit my interviews to 5/6 due to time constraints as I am conscious that my research study is a minor dissertation (10,000 words). I will consider conducting the interviews on a first come first serve basis.

E. Concise statement of *anticipated* ethical issues raised by your project. How do you intend to deal with them? Please address <u>all</u> items where your answers fell into a shaded box in the self-evaluation above. (200 words max.)

How do you intend to deal with them?

As this research study will include the use of human participants, I consider the emotional impact that this study could have. Although the focus of this study is on using DNA Genealogy testing, I acknowledge that family history is a sensitive topic for those engaging in adoption tracing. In this regard, I have discussed with my community partner the option of Aitheantas as a support for participants. I have provided the details for the HSE National Counselling service as another option of professional support to participants should the need arise. These options will ensure that adoptees are supported if they are upset or distressed.

The interviews are online one to one semi-structured interviews via the *UCC- supplied version of MS team*. The online survey will be conducted via the *UCC-Supplied Version of Google Forms*. The UCC- supplied versions of these Apps will thereby allow my data to be collected and stored in a secure location.

I have discussed the option of phone interviews with my tutor. On reflection, I have decided to conduct the one-to-one semi-structured interviews specifically over the *UCC- supplied version of MS Teams*. As MS Teams has a record function, this will aid my data collection.

F. Where will you store your data (paper and electronic files) over the duration of the project and after it has ended? How will you anonymise the data? How will you ensure no unauthorised person will be

able to access confidential research materials? (150 words max.) See Safe Data Storage on page 8 and read it prior to answering this question.

Where will you store your data (paper and electronic files) over the duration of the project and after it has ended?

I will collect the transcripts from the *UCC-supplied Google Form Survey* and store them on the *UCC-supplied version of OneDrive*.

The semi-structured interviews will be recorded via the *UCC-supplied version of MS Teams* and stored securely in the Teams application. I will transcribe the video recording and store the transcript on the *UCC-supplied version of OneDrive*. I will then delete the video recording once transcribed.

I will delete the survey and interview transcripts from my UCC-supplied version of OneDrive after the completion of the project.

How will you anonymise the data?

The survey responses will be collected anonymously. I will then transcribe the interviews and anonymise all participants e.g., participant *A*, *B*, *C*.

How will you ensure no unauthorised person will be able to access confidential research materials?

The data will be stored on a *UCC- supplied version of One Drive* over the duration of the project. I will ensure my laptop is password protected and encrypted. After the completion of the project, I will transfer the data to a member of the MSW team (UCC) for storage. I will also delete the data from my *UCC-supplied version of OneDrive*.

G. Have you discussed the ethics of your proposed research with your supervisor and has your supervisor approved what you are proposing?

Yes, I have received confirmation that my tutor has approved my proposal.

What do I show my supervisor with this form?

- 1. A copy of your *draft* data collection instrument(s) (interview guide, questionnaire, survey, focus group schedule, etc.).
- 2. A copy of your information guide for the study.
- 3. A copy of your information sheet, informed consent form and any other forms used in the research process.

Website links and helpful resources

UCC Child	UCC Child Protection Policy 2018
Protection Policy	
UCC Code of	UCC Code of Research Conduct
Research	
Conduct	
UCC Student	UCC Student Garda Vetting Policy
Vetting Policy	
IT Support for	http://sit.ucc.ie
UCC Students	

EU Commission,	https://ec.europa.eu/programmes/horizon2020/en/h2020-section/responsible-research-innovation
Responsible	http://www.rri-tools.eu/
Research and	<u>mp//www.m-tools.cu</u>
Innovation &	
H2020	
RRI Tools	
Website	
SDEC (Master br	Social Research Ethics Committee (SREC)
SREC (Master by	<u>Social Research Eurics Committee (SREC)</u>
Research and	
PhD students	
only)	
Applied Social	http://www.ucc.ie/en/appsoc/staff/
Studies Staff	
Studies Stall	
Office of	https://www.ucc.ie/en/ocla/
Corporate and	
Legal Affairs	
(OCLA)	
(• • • • • • • • • • • • • • • • • • •	
GDPR	https://www.ucc.ie/en/gdpr/

Guidelines on Safe Data Storage

As researchers, it is imperative that we can assure our participants that their data will be stored securely; this is of course particularly important where potentially sensitive personal details are involved. It is not adequate to simply say that the data will be stored safely. Exact detail is required as to the use (and location) of locked cabinets, management of audio files, encryption of laptops, electronic storage and so on. Where possible **physical data** such as survey forms etc. should be converted to electronic format as soon as possible and the originals shredded. However, if you must retain physical data then it should be safely stored on premises at UCC or in a locked cabinet in a secure location.

Treating Identifiable Data

- 1. Data should be converted to anonymous form as soon as is possible, thus opening the possibility of storing the data on OneDrive etc.
- 2. If data is not anonymised then the UCC IT Department recommend using *Research Data Store OR Departments/Schools own local secure storage, (e.g., UCC NAS, etc.) if this exists.
- 3. If identifiable data is not stored on *Research Data Store or NAS the researcher must provide a justification for this and must ensure that the laptop or PC on which the data is stored is encrypted and password protected.
- 4. Applicants should never store research data on a USB and only use an encrypted portable hard drive for short-term storage until data has been anonymised.
- 5. Applicants must consider how to maintain safe storage of their data beyond the life of their laptop/ PC to meet the 10-year requirement in the UCC Code of Research Conduct.
- 6. All laptops and PCs used to access data must be encrypted and password protected.

Treating Anonymised Data

1. If confidential data has been anonymised or if you have public or non-sensitive data, then the UCC-supplied OneDrive for Business through UCC Office 365 or Google Drive through the UCC-supplied G-Suite (formerly Google Apps for Education), can be used for data storage. The **personal** versions of OneDrive and G-Suite **should not** be used to store research data.

If you have questions about these services, please contact UCC IT Helpdesk.

*Research Data Store provides a network based shared data storage facility for the UCC Research community. It is for active research projects and is not an archive service. A Principal Investigator (PI) or Head of Department can request storage (maximum 1TB) for a research project. Research Groups will have access to 1TB of storage and folders can be shared with researchers in either the central or student domains. This service can be requested by a PI or by a Head of Department on behalf of members of a research team/students.

To make a request to use Research Data Store, visit <u>http://Servicedesk.ucc.ie</u> and select option 4 (Data Storage and NASAccess). <u>"https://www.ucc.ie/en/it/services/datastore/"</u>

UCC Device Encryption Service	http://www.ucc.ie/en/it/services/encryptionlaptop/	
UCC Staff IT Services	http://www.ucc.ie/en/it/services/staff/	List of all UCC staff IT services.
HEAnet FileSender	http://www.heanet.ie/services/hosting/filesender	HEAnet FileSender is a way to share large files. It works through your web browser and allows you to send encrypted files to any email address in a safe manner.

Information Sheet- Interviews

Thank you for considering participating in this research project "Buying your identity" - An exploration of the use of DNA Genealogy testing from the perspective of Adult Adoptees. The purpose of this document is to explain to you what the work is about and what your participation would involve, so as to enable you to make an informed choice.

The purpose of this study is to examine the experience of adult adoptees who have participated in DNA Genealogy testing. Research in this area is limited, particularly in the Irish context. As a requirement of the UCC Master's in Social Work Programme, I have to undertake a research study. This study is carried out in conjunction with Aitheantas – Adoptee Identity Rights as part of a Community Academics Research Links Project (CARL).

Should you choose to participate, you will be asked to take part in a one-to-one interview with the researcher. This interview will be video recorded over MS Teams and is expected to take 20 minutes to complete. Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the interview. Once the interview has been concluded, you can choose to withdraw from the study after it is completed, this is possible for up to two weeks after the interview. The researcher will ensure that all data will be destroyed thereafter and not used.

All of the information you provide will be kept confidential and anonymous and will be available only to the researcher and the researchers academic supervisor. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others. Once the interview is completed, the recording will immediately be transcribed by the researcher, and all identifying information will be removed. Once this is done, the video recording will also be deleted and only the anonymized transcript will remain. This will be stored on the University College Cork OneDrive system and subsequently on the UCC server. The data will be stored for a minimum of ten years as required by UCC. The information you provide will contribute to the researchers Master's in Social Work thesis in UCC. The results will be published on the CARL website (https://www.ucc.ie/en/scishop/ac/) and will be presented as part of the Master's in Social Work thesis in UCC.

We do not anticipate any negative outcomes from participating in this study. At the end of the interview, I will discuss with you how you found the experience and how you are feeling.

Should you experience distress arising from the interview, the contact details for support services provided below may be of assistance:

HSE National Counselling Service -

HSE REGION	AREA COVERED	TELEPHONE NO
CHO Area 1	Donegal, Sligo & Leitrim	1800 234 119
CHO Area 2	Galway, Mayo & Roscommon	1800 234 114
CHO Area 3	Limerick, Clare & North Tipperary	1800 234 115
CH Cork, Kerry	Cork & Kerry	1800 234 116
CHO Area 5	Waterford, Wexford, Kilkenny, Carlow & South Tipperary,	1800 234 118
CH East	South Dublin, South East Dublin & East Wicklow	1800 234 111
CH Dublin South, Kildare & West Wicklow	South West Dublin, Kildare & West Wicklow	1800 234 112
CHO Area 8	Midlands: Laois, Offaly, Longford & Westmeath	1800 234 113
CHO Area 1/8	Louth, Meath, Cavan & Monaghan	1800 234 117
CHO Area 9	Dublin North & Dublin North City	1800 234 110

For any former residents of Mother and Baby Homes seeking counselling support, the HSE National Counselling Service (NCS) is available to provide a counselling service from Monday to Friday between 9.30 and 5pm: <u>https://www.hse.ie/eng/services/list/4/mental-health-services/national-counselling-service/counselling-service-for-former-residents-of-mother-and-baby-homes/</u>

Our designated person from xxxxxxx) is also available to offer informal support.

This study has obtained ethical approval from the UCC Social Research Ethics Committee.

If you have any queries about this research, you can contact me, Denise Linehanand my research supervisor at If you agree to take

part in this study, please sign the consent form overleaf.

Consent Form- Interview

I	agree to participate in	research study.
The purpose and nature	of the study has been explained to me in writing	5.
I am participating volum	tarily.	
I give permission for m	y interview with	orded.
I understand that I can v starts or while I am part	withdraw from the study, without repercussions, icipating.	, at any time, whether before it
I understand that I can w case the material will be	vithdraw permission to use the data within two we deleted.	veeks of the interview, in which
I understand that anony	mity will be ensured in the write-up by disguisir	ng my identity.
I understand that disguing publications if I give pe	sed extracts from my interview may be quoted in rmission below:	n the thesis and any subsequent
(Please tick one box:)		
I agree to quotation/pub	lication of extracts from my interview	
I do not agree to quotati	on/publication of extracts from my interview	
Signed:		Date:
PRINT NAME:		

Information Sheet- Survey

Thank you for considering participating in this research project- "Buying your identity" - An exploration of the use of DNA Genealogy testing from the perspective of Adult Adoptees. The purpose of this document is to explain to you what the work is about and what your participation would involve, so as to enable you to make an informed choice.

The purpose of this study is to examine the experience of adult adoptees who have participated in DNA Genealogy testing. Research in this area is limited, particularly in the Irish context. As a requirement of the UCC Master's in Social Work Programme, I have to undertake a research study. This study is carried out in conjunction with Aitheantas – Adoptee Identity Rights as part of a Community Academics Research Links Project (CARL). Should you choose to participate, you will be asked to complete a UCC- supplied version of Google Forms, which will include items on the DNA Genealogy testing process, the use of social media during the DNA Genealogy testing process and whether social support would be useful for adoptees during the DNA Genealogy testing process.

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the study. All information you provide will be confidential and your anonymity will be protected throughout the study. IP addresses will not be collected at any point, meaning the data you provide cannot be traced back to you.

You maintain the right to withdraw from the study after it is completed, this is possible for up to two weeks after the interview. At this point your data will be collated with that of other participants and can no longer be retracted.

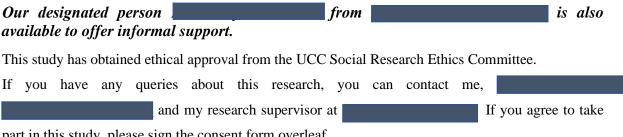
All of the information you provide will be kept confidential and anonymous and will be available only to the researcher and the researchers academic supervisor. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others. Once the survey is completed, it will be stored on the University College Cork OneDrive system and subsequently on the UCC server. The data will be stored for a minimum of ten years as required by UCC. The information you provide will contribute to the researchers Master's in Social Work thesis in UCC. The results will be published on the CARL website (https://www.ucc.ie/en/scishop/ac/) and will be presented as part of the Master's in Social Work thesis in UCC.

We do not anticipate any negative outcomes from participating in this study Should you experience distress arising from participating in the research, the contact details for support services provided below may be of assistance:

HSE	National	Counselling	Service –

HSE REGION	AREA COVERED	TELEPHONE NO
CHO Area 1	Donegal, Sligo & Leitrim	1800 234 119
CHO Area 2	Galway, Mayo & Roscommon	1800 234 114
CHO Area 3	Limerick, Clare & North Tipperary	1800 234 115
CH Cork, Kerry	Cork & Kerry	1800 234 116
CHO Area 5	Waterford, Wexford, Kilkenny, Carlow & South Tipperary,	1800 234 118
CH East	South Dublin, South East Dublin & East Wicklow	1800 234 111
CH Dublin South, Kildare & West Wicklow	South West Dublin, Kildare & West Wicklow	1800 234 112
CHO Area 8	Midlands: Laois, Offaly, Longford & Westmeath	1800 234 113
CHO Area 1/8	Louth, Meath, Cavan & Monaghan	1800 234 117
CHO Area 9	Dublin North & Dublin North City	1800 234 110

For any former residents of Mother and Baby Homes seeking counselling support, the HSE National Counselling Service (NCS) is available to provide a counselling service from Monday to between 9.30 and 5pm: https://www.hse.ie/eng/services/list/4/menta l-health-Friday services/national-counselling-service/counselling-service-for-former-residents-of-mother-andbaby-homes/



part in this study, please sign the consent form overleaf.

Consent Form- Survey

Please only proceed if you are over 18 years of age and have used DNA Genealogy testing for adoption tracing purposes.

I.....agree to participate in research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

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

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my survey responses may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/pu	blication of extracts from my survey	
I do not agree to quota	tion/publication of extracts from my survey	
Signed:		
Date:		
PRINT NAME:		

Appendix -B

Online Survey Design

<form></form>	Questions Responses 🚳	Total points: 0		
Please only proceed if you are over 18 years of age and have used DNA Genealogy testing for adoption tracing purposes and are based in Ireland. I agree to participate in research study. The purpose and nature of the study has been explained to me in writing. I am participating voluntarily. I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while lam participating. I UNDERSTAND THAT I CANNOT ASK FOR MY DATA TO BE WITHDRAWN AFTER I HAVE SUBMITTED MY RESPONSES, DUE TO THE FACT THAT THE DATA IS ANONYMOUS. I understand that diaguised extracts from my survey responses may be quoted in the thesis and any subsequent publications if I give permission below: BY TICKING THIS BUTTON AND PRESSING NEXT BELOW, YOU CONSENT TO PARTICIPATING IN THE STUDY AND AGREE TO THE TERMS ABOVE: O Yes	What will happen to the information you provide? Once the survey is completed, it will be stored on the University College Cork OneDrive system and subtor the UCC server. The data will be stored for a minimum of ten years as required by UCC. What will happen to the results? The information you provide will contribute the researchers Master's in Social Work thesis in UCC. The be published on the CARL website (https://www.ucc.ie/en/scishop/ac/) and will be presented as part of Master's in Social Work thesis in UCC. This study has obtained ethical approval from the UCC Social Re Ethics Committee. We do not anticipate any negative outcomes from participating in this study Should you experience dist arising from participating in the research, the contact details for support services provided below may to assistance: The Samaritans telephone service is available 24 hours a day: 116 123. For any former residents of Mother and Baby Homes seeking counselling support, the HSE National Conservice (NCS) is available to provide a counselling service from Monday to Friday between 9.30 and Spr of the National Counselling Service and contact details for each area are listed below. CHO Area 1 Donegal, Sligo and Leitrim CHO Area 2 Galway, Mayo and Roscommon CHO Area 3 Limerick, Clare and North Tipperary CHO Area 4 Limerick, South East Dublin and East Wicklow CHO Area 5 Waterford, Wexford, Kilkenny, Carlow and South Tipperary CHO Area 5 Midlands: Loois, Offaly, Longford and Westmeat	results of the search tress be of 0.234 119 0.234 115 0.234 115 0.234 116 0.234 116 0.234 118 0.234 111 0.234 111 0.		2
○ N0	Please only proceed if you are over 18 years of age and have used DNA Genealogy testing for adoption tran- purposes and are based in Ireland. I agree to participate in testing research study. The purpose and nature of the study has been explained to me in writing. I am participating voluntarily. I understand that I can withdraw from the study, without repercussions, at any time, whether before it start while I am participating. UNDERSTAND THAT I CANNOT ASK FOR MY DATA TO BE WITHDRAWN AFTER I HAVE SUBMITTED MY RESPONSES, DUE TO THE FACT THAT THE DATA IS ANONYMOUS. I understand that anonymity will be ensured in the write-up by disguising my identity. Luderstand that disguised extracts from my survey responses may be quoted in the thesis and any subse publications if I give permission below: BY TICKING THIS BUTTON AND PRESSING NEXT BELOW, YOU CONSENT TO PARTICIPATING IN STUDY AND AGREE TO THE TERMS ABOVE:	cing is or	Tr 	I
	∩ No			0

	Section 4 of 4	Ð	
	Survey Questions X I	9 17	
	Description (optional) Where did you hear about DNA Genealogy Testing?	-	
	Long answer text	8	
	What methods have you used for tracing your biological relatives i.e., DNA Genealogy Testing or Statutory Social Work services?		
	If you engaged with a Social Worker, what role did they play in this?		
	Long answer text		0
	If you have, do you believe it has provided you with greater access to information relating to your biological relatives? Long answer text	 ⊕ ⊥ ⊥ 	
	Do you feel the process of DNA Genealogy testing has an emotional impact for adoptees?		
	Is support necessary when DNA results are received?		
	○ No		
	If so, are these supports sufficient in Ireland or can they be improved upon? Long answer text		Ø
	Do you have any recommendations for developing support services in relation to the DNA Genealogy Testing process? Long answer text	÷	
	Long unamer text	Tr	
	If there anything you would like to add before completing this survey? Long answer text		
	Finally, I would like to invite you to discuss this research topic further through a one-to-one interview. This interview will be conducted over the UCC-supplied version of Microsoft Teams Video. Please indicate whether you would like to discuss the topic further below.		
	 Yes No 		
	If so, please provide an email address below to arrange the interview or feel free to email me at		0

Appendix C

Consent Form and Information Sheet- Interviews

Questions Responses () Total points: ()	
Consent Form-Interviews	⊕ ₽ Tr
The purpose and nature of the study has been explained to me in writing. I am participating voluntarily. I give permission for my interview with the bevideo recorded. I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while i am participating. I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deted. I understand that anonymity will be ensured in the write-up by disguising my identity.	
I understand that disguised extracts from my interview may be quoted in the thesis and Master of Social Work presentations as well as any subsequent publications if I give permission below: Iagree to participate in YOUR NAME AND EMAIL ADDRESS BELOW. Thank You. Long answer text	
Please tick one box: * I agree to quotation/publication of extracts from my interview I do not agree to quotation/publication of extracts from my interview	Ø

Information Sheet used for MS Teams Interviews

Thank you for considering participating in this research project- An Exploration of Adult Adoptees Experiences of DNA Genealogy Testing. The purpose of this document is to explain to you what the work is about and what your participation would involve, so as to enable you to make an informed choice.

The purpose of this study is to examine the experience of adult adoptees who have participated in DNA Genealogy testing. Research in this area is limited, particularly in the Irish context. As a requirement of the UCC Master's in Social Work Programme, I have to undertake a research study. This study is carried out in conjunction with Aitheantas – Adoptee Identity Rights as part of a Community Academics Research Links Project (CARL).

Should you choose to participate, you will be asked to take part in a one-to-one interview with the researcher. *This interview will be video recorded over Microsoft Teams Video and is expected to take 20 minutes to complete*. A link will be sent to you via email prior to the email, you do not need to have the Microsoft Teams App and can use the web version for the interview.

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the interview. Once the interview has been concluded, you can choose to withdraw from the study after it is completed, this is possible for up to two weeks after the interview. The researcher will ensure that all data will be destroyed thereafter and not used.

All of the information you provide will be kept confidential and anonymous and will be available only to the researcher and the researchers academic supervisor. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others. Once the interview is completed, the recording will immediately be transcribed by the researcher, and all identifying information will be removed. Once this is done, the video recording will also be deleted and only the anonymized transcript will remain. This will be stored on the University College Cork OneDrive system and subsequently on the UCC server. The data will be stored for a minimum of ten years as required by UCC. The information you provide will contribute to the researchers Master's in Social Work thesis in UCC. The results will be published on the CARL website (https://www.ucc.ie/en/scishop/ac/) and will be presented as part of the Master's in Social Work thesis in UCC.

We do not anticipate any negative outcomes from participating in this study. At the end of the interview, I will discuss with you how you found the experience and how you are feeling. Should you experience distress arising from the interview, the contact details for support services provided below may be of assistance:

The Samaritans telephone service is available 24 hours a day: 116 123.

For any former residents of Mother and Baby Homes seeking counselling support, the HSE National Counselling Service (NCS) is available to provide a counselling service from Monday to Friday between 9.30 and 5pm. Details of the National Counselling Service and contact details for each area are listed below.

HSE REGION	AREA COVERED	TELEPHONE NO
CHO Area 1	Donegal, Sligo & Leitrim	1800 234 119
CHO Area 2	Galway, Mayo & Roscommon	1800 234 114
CHO Area 3	Limerick, Clare & North Tipperary	1800 234 115
CH Cork, Kerry	Cork & Kerry	1800 234 116
CHO Area 5	Waterford, Wexford, Kilkenny, Carlow & South Tipperary,	1800 234 118
CH East	South Dublin, South East Dublin & East Wicklow	1800 234 111
CH Dublin South, Kildare & West Wicklow	South West Dublin, Kildare & West Wicklow	1800 234 112
CHO Area 8	Midlands: Laois, Offaly, Longford & Westmeath	1800 234 113
CHO Area 1/8	Louth, Meath, Cavan & Monaghan	1800 234 117
CHO Area 9	Dublin North & Dublin North City	1800 234 110

Outside of office hours, Connect Counselling provides telephone support. This service is available between 6pm and 10pm each day (7 days a week) on 1800 477 477. Our designated from Aitheantas is also available as informal

support.

This study has obtained ethical approval from the UCC Social Research Ethics Committee. If you have any queries about this research, you can contact me, Denise Linehanand my research supervisor at