

https://dspace.org/

DNA profiling of unidentified human remains in the South African context: an ethico-legal analysis

Krysztofiak, Bozena

2016
http://hdl.handle.net/10539/23240

Downloaded from a DSpace repository. https://dspace.org/

DNA PROFILING OF UNIDENTIFIED HUMAN REMAINS IN THE SOUTH AFRICAN CONTEXT: AN ETHICO-LEGAL ANALYSIS

Bozena Krysztofiak

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in Bioethics and Health Law

Johannesburg, December 2016

DECLARATION

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I BOZENA KRYSZTOFIAK (Student number: 511713) am a student registered for the degree of MSc (Med) Bioethics & Health Law in the academic year 2016.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: B. Krystofiak Date: 13/12/2016

To my son, Tytus

ABSTRACT

Due to the inherent sensitive character of human genetic material, when employing DNA-based methodology in identification of human remains, clear ethical guidelines and well implemented law are necessary. With this in focus, the study determines and validates a set of morally justifiable ethical standards drawn from universal principles and human rights which rest on the value of respect of human dignity. In South Africa, The Criminal Law (Forensic Procedures) Amendment Act was commenced in 2015. While the terms of the Act mainly deal with the establishment and functioning of the National Forensic DNA Database of South Africa for the purposes of criminal justice, it also provides for the identification of missing persons and unidentified human remains. To be fully compliant with ethical standards and human rights, few areas of the Act needing attention and improvement during a further implementation process are highlighted. This study concludes with several recommendations to promote meeting the recognised ethical standards by the local DNA-based programme of identification of human remains.

ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to my Supervisors, Doctor Jillian Gardner and Doctor Christopher Wareham, for the valuable help and assistance I have received from them during writing of this research report. I thank them both for their constructive critique during the review process of the draft and all the support they have offered to me in my endeavours.

Bozena Krysztofiak

Johannesburg

August 2016

TABLE OF CONTENTS **PAGE**

DECLARATION ii
DEDICATION iii
ABSTRACT iv
ACKNOWLEDGEMENTS v
TABLE OF CONTENTS vi
LIST OF ABBREVIATIONS x

CHAPTER 1: BACKGROUND AND STUDY OBJECTIVES

1.1 Introduction 1
1.2 Ethical and human rights concerns 2
1.3 South African laws 3
1.4 Study objectives 3
1.5 Outline of the study 4

CHAPTER 2: IDENTIFICATION OF UNIDENTIFIED HUMAN REMAINS

2.1 Introduction 6
2.2 Identification process in South Africa 6
2.3 DNA profiling 8
2.3.1 DNA structure and its applications for comparison purposes 9
2.3.2 Sources of DNA samples 10
2.3.3 DNA methodology 11
2.3.4 Maternal and paternal lineage systems 13
2.3.5 From DNA sample to identification 13

CHAPTER 3: HUMANITARIAN AND SOCIETAL VALUE OF IDENTIFICATION

3.1 Introduction 15
3.2 Legal matters 15
3.3 Psychological aspects 17
3.3.1 Bereavement and grief 17
3.3.2 Burial 18
3.3.3 The missing 18

3.4 Societal value of identification 19
3.4.1 In disasters 19
3.4.2 In war and conflict 20
3.4.2.1 Bosnia 22
3.4.2.2 Iraq 22
3.4.2.3 South Africa 23

CHAPTER 4: ETHICAL CONCERNS RELATED TO DNA IDENTIFICATION

4.1 Introduction 26
4.2 Social issues 27
4.3 Resource allocation 28
4.4 Incidental findings 31
4.5 Research 33
4.6 Informed consent 34
4.7 Forensic databases 35
4.7.1 Personal data 35
4.7.2 Familial searching 36
4.7.3 Missing persons database 37
4.8 Concluding remarks 38

CHAPTER 5: ETHICAL STANDARDS FOR DNA IDENTIFICATION

5.1 Introduction 40
5.2 Humanitarian aspects 40
5.2.1 Compassion and humanism 41
5.2.2 Notification of family members 42
5.3 Universal ethical principles 42
5.3.1 Human dignity and human rights 43
5.3.1.1 The dignity and rights of the dead 43
5.3.1.2 The rights of the bereaved 44
5.3.2 Benefit and harm 45
5.3.3 Autonomy 46
5.3.4 Consent 47
5.3.5 Respect for vulnerability 47
5.3.6 Privacy and confidentiality 48

5.3.7 Equality, justice, equity 49
5.3.8 Non-discrimination and non-stigmatisation 49
5.3.9 Respect for cultural diversity and pluralism 50
5.4 Meeting the standards 50
5.5 Concluding remarks 51

CHAPTER 6: ETHICAL ASSESSMENT OF THE EXISTING LAW ON DNA IDENTIFICATION IN SOUTH AFRICA

6.1 Introduction 54
6.2 The Bill of Rights 55
6.2.1 Equality 56
6.2.2 Human dignity 56
6.2.3 Freedom and security of the person 56
6.2.4. Privacy 56
6.2.5 Freedom of religion, belief and opinion 57
6.3 The DNA Act 57
6.3.1 Collection of DNA samples 58
6.3.2 The National Forensic DNA Database of South Africa 59
6.3.3 Retention and disposal of DNA samples 61
6.3.4 Retention and disposal of forensic DNA profiles 61
6.3.5 Uses of DNA samples and profiles and access to the database 61
6.3.6 Familial searching 61
6.3.7 Ethical oversight 62
6.4 Concluding remarks 63

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

7.1 Introduction 64
7.2 Overall conclusions 65
7.2.1 Guiding principles 65
7.2.2 Regulatory framework in South Africa 66
7.2.3 Practical applications 67
7.3 Recommendations 68
7.3.1 DNA profiling as an aid to other identification methods 69
7.3.2 Resource allocation 69
7.3.3 Informed consent and voluntary participation 70

7.3.4 Notification of families 71
7.3.5 Respect for the autonomy of the families 72
7.3.6 Protection of privacy and confidentiality 72
7.3.7 Chain of custody 73
7.3.8 Secondary uses of DNA samples and DNA profiles 73
7.3.9 Oversight 73

REFERENCES 75
APPENDIX A: Ethics clearance certificate 84

LIST OF ABREVIATIONS

DNA	Deoxyribonucleic Acid
ICRC	International Committee of the Red Cross
IFRC	International Federation of Red Cross
PAHO	Pan American Health Organization
PCR	Polymerase Chain Reaction
SAPS	South African Police Service
STR	Short Tandem Repeats
TRC	Truth and Reconciliation Commission
UNESCO	United Nations Educational Scientific and Cultural Organisation
VNTR	Variable Number of Tandem Repeats

CHAPTER 1: BACKGROUND AND STUDY OBJECTIVES

1.1 Introduction

This study provides a South African ethical perspective on the application of DNA (deoxyribonucleic acid) profiling in the identification of unidentified deceased. The study reflects my personal interest in dealing with this dynamically developing field of forensic sciences which arose, in part, out of contact with distraught family members of deceased persons during the course of my professional duties as a forensic pathologist.

As I have witnessed, the distress of the relatives is intensified when there is uncertainty about the identity of the deceased. Inability to identify delays the release of the body of the deceased from the Forensic Pathology Service facility for burial. Identification utilising DNA carries its own inherent issues that need to be managed professionally by all parties involved in the process. In managing these issues, guidance may be sought from bioethical norms and consideration of human rights.

The identification of a deceased person is of paramount importance for legal and social reasons. The attribution of an identity to a deceased allows the family to grieve for the loved one and permits a culturally appropriate burial to take place. The inability to accurately identify the deceased constitutes a major legal problem in terms of succession and criminal investigations into cases of unnatural deaths. Identification using DNA technology may, in certain cases, be the only option available while dealing with severely decomposed, burnt, comingled or fragmented bodies. This may involve a single person in certain situations or multiple victims following, for instance, natural disasters, terrorist attacks or traffic accidents (1)(2).

DNA profiling technology has been developed within the last 30 years (3). In the case of human remains that are impossible to identify by visual appearance, fingerprints or other characteristic features, the DNA present in the components of the body cells, extracted from the remains, is analysed. The particular sequences of the human genetic material contained in cellular nuclei or in mitochondria are unique and allow for identification of individuals. The generated DNA profile is compared with a known

DNA profile of a missing person obtained from the personal items (direct matching) or with the DNA profile of the family members (kinship matching) (4).

This research seeks to determine what legal regulatory provisions and professional ethical guidelines are needed in South Africa to ensure the moral and ethical considerations relating to DNA identification of unidentified human remains are addressed. To answer this question, this paper systematically examines the ethical aspects of DNA identification and related local law in order to formulate a set of ethical guidelines and policy recommendations that may be useful for forensic professionals and officials concerned with this process in South Africa. When introduced into practice these recommendations should enable the personnel dealing with DNA identification procedures to confidently face challenges of DNA profiling.

1.2 Ethical and human rights concerns

The process employing DNA for identification of deceased persons prompts ethical and human rights considerations relating to invasion of genetic privacy (1)(5), social and racial issues (5)(6), unintended findings (4) and research (7), particularly in the post conflict and post disaster setting (8)(9)(10)(11). A vast number of international publications exist on ethical aspects and human rights concerns associated with the identification process of unidentified human remains using DNA technology. It is evident that these subjects are being keenly deliberated by bioethicists (5)(7)(12). The issues that are being discussed relate to deceased persons and their living relatives.

Because DNA profiling techniques delve into the most intimate information of any human being and are rather poorly understood by the public, the DNA identification process has been met with apprehension (5)(13). On the other hand, facilitating DNA profiling of individuals and establishing of forensic databases creates high expectations for its crime-fighting capabilities, particularly in crime-ridden South Africa (14).

Despite the importance of the matter, local literature on the topic is scarce. Employing a popular search engine like Google and a search of a specialised medical literature database PubMed returns only few, namely four, local publications overtly dealing with ethical issues of DNA identification (10)(15)(16)(17). The

research and publications which exist are primarily concerned with the value of DNA profiling for evidentiary purposes in the criminal justice system (18)(19) or assessing ethical matters in relation to criminal forensic databases (20).

The subject of ethical considerations in DNA identification of missing persons and unidentified human remains was brought to light by bioethicists when ethical problems were encountered during identification operations following natural disasters of the last decade or national conflicts. This study adds an additional perspective on the topic and underscores its significance. The discussion on the ethical and social concerns regarding the DNA identification process outside the criminal justice system and essential ethical standards illuminates certain pivotal concepts relevant to the subject and perhaps clarifies some misconceptions. Critical examination of the relevant local laws places the issue in the South African context and the concluding recommendations strive to watch over individuals and society while protecting the local DNA identification programme.

1.3 South African laws

Successful application of the DNA identification process which is compassionate and mindful of human rights requires not only specialised knowledge, appropriate training and clear protocols but also calls for specific human sensitivities from the officials dealing with the process. The fundamentals of the approach to the constantly developing subject can be found in the Bill of Rights of the Constitution of the Republic of South Africa, 1996 (21) with its focus on progressiveness and human rights, and recently in the Criminal Law (Forensic Procedures) Amendment Act, 2013 (22) commenced on 31 January 2015, with exclusion of section 2 (23).

1.4 Study objectives

This study aims to raise awareness of the vitally important ethical issues concerning the DNA identification of unidentified human remains and to examine the subject in the South African context.

The following objectives are pursued in this research project:

a) To give an account of the ethical concerns related to DNA identification in unidentified human remains with special attention to the post-disaster and post-war settings
b) To formulate and justify prescriptive normative positions on the major ethical issues related to DNA identification of unidentified human remains
c) To critically evaluate the current South African law on DNA identification against the prescriptive normative positions articulated in subsection b) above

1.5 Outline of the study

This report begins with the introductory chapter that presents the background for the study, the main research question and study objectives.
The second chapter offers an overview of identification procedures of the deceased persons in South Africa and methodology of DNA identification process used internationally and locally.
The third chapter demonstrates the value of identification of the deceased to their families and entire communities and makes the significance of the recognition of the deceased for legal, psychological and societal reasons evident.
Then, the fourth chapter proceeds to illustrate the main concerns being raised in connection with DNA identification methodology such as genetic privacy, justice, research and informed consent.
Next, in the fifth chapter, general ethical standards to conform to when dealing with DNA identification are formulated and justified. These standards are drawn from universal ethical principles based on respect for human dignity and argument is made that observation of these norms and well-implemented related laws are obligatory. These ethical guidelines seek to serve as an aid for professionals and officials included in the process of identification of missing persons and human remains.
The sixth chapter, based on those previously formulated norms, offers analysis of South African statute specifically addressing DNA identification, the Criminal Law (Forensic Procedures) Amendment Act, 2013 (22). The interest of this research is limited to the provisions of the Act concerning missing persons and unidentified human remains.

The final, seventh chapter, provides a summary of this research on the DNA identification of unidentified human remains. This closing chapter outlines policy recommendations drawn upon previously validated ethical standards. The purpose of these recommendations is to guard against personal and societal harms and aid in the provision of equitable access to a service that remains, to some extent, privileged.

CHAPTER 2: IDENTIFICATION OF UNIDENTIFIED HUMAN REMAINS

2.1 Introduction

Identification of deceased persons constitutes a legal requirement worldwide. Registration of death of a person is a prerequisite for winding up the deceased's estate and demands accurate attribution of identity. The failure to identify the deceased poses problems for succession and negatively influences criminal justice if death was due to unnatural causes.

Identification of a deceased carries humanitarian and social value. The attribution of a name to the deceased assists all legal processes that are required to occur; facilitates discharge of financial duties to the beneficiaries of the deceased estate and life policies; allows the grieving process to proceed for the loved ones and permits culturally appropriate burials.

This chapter outlines the procedure for the identification of the deceased that takes place in South Africa. This will include an exploration of when the DNA analysis is indicated and a brief description of the DNA profiling methodology that is currently employed both locally and internationally.

2.2 Identification procedure in South Africa

To advance the understanding of identification of deceased persons, this section describes the general steps which take place in the forensic pathology facilities and in forensic laboratories in South Africa. This overview identifies the personnel involved in identification of human remains and the role they play to set the scene for discussion on ethical standards of conduct in the following chapters.

In South Africa a death of a person must be registered in terms of the Births and Deaths Registration Act, 1992 (24). For this purpose a Notice of Death/Stillbirth, DHA -1663 form, is issued by a medical practitioner or professional nurse. This form contains identification particulars of the deceased, including their name, and is submitted to Home Affairs in order to obtain the Death Certificate.

Usually, in cases of natural death the identity of a deceased person is confirmed by an identity document.

When the cause of death is deemed to be unnatural, the body is directed to a Forensic Pathology Service facility and if the deceased's appearance is unchanged in death all that is required for identification is viewing by the relative or any person who personally knew the deceased. The identity is then verified by appropriate documentation (25).

However there are instances when the deceased's body is disfigured and visual identification is made difficult or completely precluded. Bodies which are damaged by fire, mutilated or decomposed may necessitate the employing of non-scientific and complex scientific methods to learn and confirm their identity. In certain situations, for example in traffic accidents, building collapses, natural disasters or terrorist attacks, single or multiple victims may be involved and require precise identification.

The commonly utilised non-scientific methods alternative to visual facial identification are the recognition of special identifying bodily features such as tattoos or scars and the recognition of clothing and personal items which provide circumstantial evidence of identity.

On the other hand, the scientific methods of comparison of ante mortem medical and dental records with post mortem findings, evaluation of fingerprints and comparative DNA analysis ensure direct proof of identity (1)(26).

The institutions involved in the identification process for forensic purposes in South Africa are the Forensic Pathology Service falling under the Department of Health, South African Police Service and the Forensic Science Laboratory of the South African Police Service.

Forensic Pathology Service facilities participate in the sampling of tissue and blood from the bodies for the purpose of DNA analysis, obtaining the fingerprints and photographs, post mortem radiographic examination, appropriate recording of personal items and assessment of biological features. Currently there are 127 Forensic Pathology Service facilities in South Africa; the data for 2016 was obtained from Mrs Grove, the Director of Forensic Pathology Services in the National Department of Health, Pretoria. These facilities handle the medico-legal investigation of cases of un-natural death to assist judicial processes. The large numbers of cases

which require DNA sampling to facilitate identification include decomposed bodies, bodies charred in fires, bodies fragmented and comingled. Learning the exact figures of these cases investigated in the South African medico-legal mortuaries in the past and at present is beyond the scope of this study.

The Inquests Act 58 of 1959 (27) entrusts the duty of investigation of the circumstances of death due to other than natural causes to police officers. The Investigating Officer interacts with Local Criminal Record Centre and Home Affairs to coordinate utilisation of fingerprints for identification. The police officer investigating the death is also responsible for obtaining the ante mortem photographs and medical records, and making arrangements with relatives for obtaining DNA samples. The samples will prove useful for DNA profiling through comparative analysis when necessary (26). The samples commonly collected from the living relatives are blood and buccal (cheek) swabs. This process takes place in clinical health facilities; buccal swabs may be performed by personnel of the Victim Identification Centre of the Forensic Science Laboratory during visits to the family members. The personal use items being a source of DNA are also collected from the deceased's household. The investigating officer transports the DNA samples from the Forensic Pathology Service and clinical health facilities to the Biology Unit of the Forensic Science Laboratory for evaluation. On occasion the personnel of the Victim Identification Centre engage directly in the collection of suitable DNA samples from the human remains that are in custody of the Forensic Pathology Service.

The blood and tissue samples remain in cold storage at the Laboratory before they are processed. Forensic experts analyse the biological samples using the available DNA identification technology. The results of the DNA testing are entered into the Laboratory database and evaluated using specialised computer software for a match with an existing or recently created record. A positive match between the DNA profile from the unidentified deceased and the DNA profile of the known reference sample finally assigns a name to the deceased person.

2.3 DNA profiling

Inability to identify deceased persons is an issue experienced globally. Large numbers of deceased remain unidentified in state mortuaries that fulfil forensic

functions, not only locally in South Africa (28) but in other countries as well (29).
A body's condition may preclude direct visual identification resulting in that body remaining unclaimed and unidentified. In such a situation special procedures for identification are required.

The identification of comingled human remains and bodies that are so damaged or fragmented that they cannot be identified using standard methods calls for highly specialised techniques of identification, such as the DNA profiling (30).
Being the most effective method of non-standard identification genetic testing has become the mainstay of victim identification in disaster situations (30)(31). DNA profiling in disaster victim identification has an advantage of enabling the identification of small parts of human remains recovered. This is consistent with an expectation of the public to do so (32).

To provide an insight into this developing technology, the following sections explain the structure of a DNA molecule, sources of samples for DNA profiling and basic principles of currently used matching methods. The appreciation of the special and intricate character of human genetic material puts the complexity of the DNA identification methods and associated ethical challenges emphasised in this study into perspective.

2.3.1 DNA structure and its application for comparison purposes

Living organisms are composed of tissues arranged into organs; these are arranged into organ systems. The small structural units of tissues are called cells. Cells serve the elementary function of life (33).

DNA is an intracellular macromolecule that is capable of storing biological information. It is present in all cells of the body, in the nucleus in the chromosomes and in the cytoplasm in the mitochondria. The genetic information kept in the nucleus of the cell is inherited from both parents during the process of conception. The mitochondrial DNA carries the genetic material inherited only from the mother.

The biochemical components of the DNA polymer, the nucleotides built of nucleotide bases, sugar deoxyribose and phosphate group, are organised in a specific configuration that determines the double helix structure of the macromolecule. The

double helix is constructed of two wound strands of multiple nucleotides with a frame made of deoxyribose-phosphate complexes positioned on the sides of the helix and joined in the middle by complementary nucleotide bases. The attributes of the helical structure of the DNA are responsible for the linear arrangement pattern of carried genetic information making it readable and transmittable to the next generation (33).

The possibility of discovering the utmost personal details of a person calls for establishment of fundamental ethical standards to deal with the challenge of invasion of genetic privacy and related issues. The identification of basic ethical principles and their application are at the heart of this study.

The sequence of paired nucleotide bases along the double helix determines human genetic information. The segments of the DNA that “code” for the structure and function of the proteins constitute “genes”. Between the coding segments of the DNA polynucleotide chain that play a role in transmission of the genetic information are interposed non-coding segments of variable length (33). Relatively, there is not much variation in the protein-coding genes, quite opposite to the non-coding regions. The different numbers of the short sequences of the nucleotide bases being repeated in the non-coding segments regulate the length of these regions and this variability determines distinctly different personal genetic profiles that can be scientifically ascertained and used to differentiate between individuals. Only identical twins have identical DNA profiles, all other individuals vary (18). The conventional methods of DNA profiling based on nuclear DNA require biological samples with nucleated cells, however mitochondrial DNA analysis may be conducted on anucleated material like hair without roots, in skeletonised human remains or very degraded DNA material (34).

2.3.2 Sources of DNA samples

The identification process using human genetic material employs comparative analysis of the DNA sample collected from the remains post mortem and DNA material left behind while the deceased was still alive or obtained from the close living relatives. DNA profiling aims to assess the match between the biological material and the deceased person or between two, and sometimes more, persons (30).

The post mortem DNA sample may be sourced as blood or tissue like muscle, bone, teeth, hair and nails, depending on the state of preservation and availability. External factors such as exposure to the elements, microbial and chemical contaminations and length of post mortem period negatively influence the condition of DNA. The hard tissues are less susceptible to environmental factors during the post mortem interval and may be the only source of genetic material for analysis (30). Rich sources of residual genetic material are left by each person every day on their tooth brushes as buccal cells, on their hair brushes as hair or it may be preserved as mementoes in a form of lock of hair, milk teeth or dried umbilical cord. The personal DNA from all these items may be compared by the DNA laboratory with post mortem samples from the remains in “direct profile matching”.

When the personal items or tissue samples are not available there is an option of performing a “kinship analysis” using the DNA containing samples from the living family members. The samples commonly sought from the relatives are blood or the less invasive, buccal swab. In cases where the reference genetic material for comparison is not available or the analysed post mortem sample is too degraded to assure a successful DNA profile, the identification of the deceased using DNA will not be possible (1).

2.3.3 DNA methodology

The method of personal identification based on a technique called minisatelite hybridisation was first described by Alec Jeffreys in 1985 and became known as “DNA fingerprinting” (30)(35) as it created a DNA pattern specific to an individual with the exception of identical twins. Further developments in DNA technology have improved sensitivity and discrimination of the DNA methods.

The introduction of the variable number of tandem repeats method (VNTR) facilitated the interpretation of the DNA profile. The DNA amplification technique, polymerase chain reaction (PCR) described at the end of the 1980s, allowed for analysis of minute quantities of biological material.

The development of the new method of testing which allowed for analysis of the repeat motifs lengths shortened to several nucleotides, the short tandem repeats method (STR), permitted successful analysis of even degraded DNA.

The creation of databases that store digital DNA profiles made comparative analysis between the reference samples and samples being evaluated less complicated (35).

At present, the standard method employed in DNA profiling internationally (19)(30) and in South Africa (18)(19) is the short tandem repeats method (STR). It is based on differing numbers of repeating sequences of nucleotide bases along the non-coding regions of DNA in different individuals. The number of repeats is analysed in the selected sites (loci) on multiple chromosomes, measured and subsequently the computerised printout is generated (3). The configuration of the number of repeats specific for each individual in the standard loci reveals this person's unique DNA profile pattern and can be analysed by special analytical kits (19)(30)(34). The high discrimination ability of the short tandem repeats analysis makes it a method of choice in mass disasters (30).

In South Africa, nine STR markers and amelogenin marker for gender determination are utilised to probe the DNA profile (3)(18). The commercially available profiling kit of this type is AmpFISTR Profiler Plus™ PCR kit (16)(18) employed by the forensic biology laboratory of SAPS. The profiling kit AmpFISTR Identifiler Plus™ PCR kit has capacity to analyse 16 markers including amelogenin and represents an upgraded version to be used in the near future (16). The SAPS laboratory does not use mtDNA technology (36).

The Profiler Plus DNA-based human identification system is suitable for fresh samples and finds successful application in South Africa. The profiling of DNA from old human skeletal and charred remains with degraded DNA is better done using smaller mini-STR targets. The mini-YSTR system utilising the STR targets on the Y chromosome are appropriate for identification of human remains from mass graves as they are suited for determination of gender and paternal lineage. The Forensic DNA Laboratory at the University of the Western Cape tasked by the National Prosecuting Authority with identification of the human rights cases in South Africa currently uses 13 loci STR analysis and is busy researching Y-STR markers, mini-STR markers and mtDNA technology (36).

The likelihood of a match by chance depends on the number of markers analysed and polymorphism at the examined loci.

The power of discrimination with ten markers analysis signifies a statistical likelihood of a false match between two individuals to be approximately one in a billion (3).

2.3.4 Maternal and paternal lineage systems

Since the mitochondrial DNA is inherited exclusively from the maternal side it is utilised for matching within the maternal lineage, which may be from any relative from the maternal side. Although the mitochondrial DNA is more readily available for analysis, the strength of the match maybe challenging to ascertain due to the fact that it is shared even with distant members of the maternal lineage (1)(34).
The X and Y sex chromosomes find their utility in the determination of paternity as the X chromosome is inherited, mostly unchanged, by a daughter from her father and the Y chromosome is exclusively inherited by a son from his father.
The X sex chromosome in a female individual may be used to ascertain the identity of her sister who shares the X chromosome from the same father (35). Matching with paternal relatives using the Y sex chromosome in male individuals may be less effective than routine short tandem repeats analysis of autosomal DNA (1)(34) and requires further testing due to some genetic material sharing between unrelated males (35).

2.3.5 From DNA sample to identification

This section serves to explain how the result of the DNA analysis in a digital form, resembling a barcode, results in an interpretation that proclaims a “match” confirming the identity of the analysed sample.

The current standard genetic identification methodology is based on direct sequencing of the DNA samples (30) resulting in digital DNA profiles (3)(19).
The DNA profile created from unidentified human remains is compared with a DNA profile of the reference sample in direct matching or kinship analysis. An appropriate methodology, suitable for the available samples and circumstances is utilized.
The reference samples for kinship analysis that are obtained from immediate relatives offer the best results (1).
If the received DNA profiles correspond, a statistical calculation of the likelihood of a match within a given population is performed. An evaluation of the probability that a random individual in this particular population would have an identical set of analysed DNA markers takes place (18). Hence the successful analysis is dependent on access to databases containing DNA profiles (30)(34).

The end result of an interpretation of the statistical probability may be either a “match”, “non –match”/ “exclusion” or “inconclusive”. The positive result, a “match”, means that there were no observable differences between the samples, the samples are genetically “concordant” at the examined loci and that the profiles have originated from a “common source”. The negative result, an “exclusion”, means the obtained profiles are different and “may have originated from different sources” (19).

DNA profiling is a remarkable addition to traditional methods of identification of individuals and is frequently a deciding factor. It requires an appropriate setting with access to modern technologies. This method is costly; it however may ensure the proper identification of otherwise unidentifiable human remains which provides relief for families and in some cases entire communities (1).
In complex matching, where direct matches are not available or the remains of several related persons have to be profiled, an approach combining multiple identification methods is appropriate (31) to ensure success.

This chapter has highlighted the key aspects of the DNA identification process: the main stakeholders, the procedures and the complexity of DNA methodology. The humanitarian and societal value of DNA profiling in identification of human remains is discussed in the following chapter.

CHAPTER 3: HUMANITARIAN AND SOCIETAL VALUE OF IDENTIFICATION

3.1 Introduction

The previous chapter offered a review of identification procedures in South Africa and the biological basis for utilisation of DNA in the identification process. To further advance an insight into the subject of this research, the value of positive identification of deceased persons is explored. This chapter underscores the importance of the identification of the dead for family members who outlive the deceased and for communities affected by mass disaster, conflict and war.

Successful identification of the deceased person constitutes one of the main purposes of the medico-legal investigation of death and engages the police, forensic pathologists, radiologists, odontologists and forensic scientists. Identification of human remains as a topic vital to any forensic pathologist features in general and more specialised forensic pathology textbooks.

The popular and widely respected textbook by Knight and Saukko (37) can serve as an example. In the chapter on the subject the authors include a comprehensive listing of purposes of establishing the identity of the deceased. These objectives include informing the concerned relatives for humanitarian reasons; to record the identity for burial purposes and for statistical and official use; to confirm death for the legal purpose of resolving deceased estate obligations; to provide for the resolution of financial matters in the form of life policies pay-outs and other reimbursements and to facilitate inquiries by the police and courts into the death.

3.2 Legal matters

This section deals with the value in the identification of a deceased person as it relates to the legal matter of succession, dissolution of marriage and financial recompenses.

The death of a natural person terminates the existence of that person as a legal subject (38). Knowing the identity of a deceased person is of vital consequence for

the surviving relatives from a legal standpoint. Difficulties in identification of the body of the deceased or the absence of the body when the person is missing poses potential problems for legal procedures to take place, such as winding up of the estate, inheritance, dissolution of marriage and payments of due financial compensations. Certain laws determine and enable these procedures in South Africa.

The Inquests Act (27) provides for legal declaration of the identity of the deceased including instances where the body is not available for identification. Upon completion of the inquest into the death of a person the judicial officer makes a finding as to the identity of the deceased. At an inquest where the body of the alleged deceased has been destroyed, not found or recovered and “the evidence proves beyond a reasonable doubt that a death has occurred” (27) the presiding judicial officer makes a relevant finding and may proclaim the person dead (38).
In cases where a person has gone missing and there is no body or the identification of the deceased cannot be carried out in a direct manner, the legal processes assist in the termination of the legal existence of that person. In respect of a person who died of unnatural causes, the High Court may grant an order of presumption of death.

The presumption is issued on a balance of probabilities. The presumption of death order is usually issued more readily if the circumstances indicate a high probability that the person may be dead. When the court is reluctant to issue a presumption of death order the court may grant an order to administer the estate so that the financial issues may be concluded. The presumption of death provides for the declaration of dissolution of marriage by death in terms of the Dissolution of Marriages on Presumption of Death Act 23 of 1979 (38). Furthermore it provides for appropriate court orders for the division of the deceased’s estate between the successors (39). Any drawing out of these legal matters may place the dependants in severe financial turmoil.

The presumption of death order does not however mean that the person is in fact dead (38). Although there are legal provisions in place for the circumstances of presumed death as demonstrated in this section, the value of direct confirmation of death of a person cannot be underestimated. Difficulties in identification of the deceased influence the ability to prove death and have not only legal and economic effects but deep psychological consequences for the family members

(40)(41)(42)(43). Lengthy administrative processes that may be required do not facilitate closure which relatives desperately need after the death of their beloved.

To provide more context for the subject of this research and increase awareness of the effects the identification efforts have on an individual and group, the following sections explore the psychological and societal aspects of recognition of the dead.

3.3 Psychological aspects

This section deals with psychological consequences of losing a loved one, achieving closure and the misery of those who experience uncertainty regarding the fate of their beloved in cases where the person is missing or the body cannot be identified.

3.3.1 Bereavement and grief

The death of a relative through prolonged illness gives some time for an adjustment to the thought of death coming and perhaps for some preparation. A sudden and unexpected loss comes as a surprise and shock making the experience more difficult to deal with. Bereavement and grief are widely recognised mental health matters that nowadays receive well deserved attention from professionals and the public. Numerous organisations and professionals, including specialised grief counsellors, take part in helping people go through their grief process and return to their usual lives (41)(42)(44)(45). The term bereavement describes a state following a loss of a beloved person through death. Grief, a reaction to the loss, is of a psychological and physical nature, the suffering is emotional and somatic. Emotional manifestations of the loss experienced by the relatives may include anger, sadness, guilt and anxiety (40)(41). The psychological effects may be accompanied by physical reactions of disturbances in sleep and appetite, and development of somatic illness (40).

People grieve for their loved ones in different ways and for different lengths of time. Some may never recover fully from the loss they experience. Grief is frequently complicated following a sudden or traumatic death.
Having a body of a loved one buried whilst observing the necessary cultural rituals is an important factor in adaptation to the loss and resolution of grief (46).

3.3.2 Burial

Identification of the body allows for the remains to be returned to the family and the burial to take place with observation of cultural traditions and religious practices. A funeral according to the established rituals provides some relief to the grieving family members and allows for an appropriate farewell, particularly in cases of sudden death. The laying to rest of the deceased in a known place, perhaps of his or her choice gives the surviving relatives the feeling of fulfilling the wishes of their beloved and gives them an opportunity to commemorate. Conducting religious ceremonies over the remains of the deceased assures the appropriate transition to eternal rest (46).

The body of the deceased person is a material object and as such has a symbolic value to the individuals and groups of all cultures. It grants a bond between the dead and the surviving persons similar in nature to reverence of the object of worship. The erected grave memorializes the deceased and has a profound meaning for the family and community members (46). It is therefore imperative to make all possible efforts to identify the remains when considering familial aspects.

3.3.3 The missing

When a loved one vanishes and the body is not found or it cannot be easily identified due to damage, decomposition or the existence of multiple victims, the uncertainty, of whether they are dead or alive, well or maybe needing help, causes enormous suffering to the families.

In her analysis of ambiguous loss, Boss (42), gives a touching description of mothers relentlessly searching for their sons and adult children looking for their fathers lost at war while formulating an answer to the frequently posed question: “Why is having a body so important?”

Boss concludes that viewing of the body is fundamental to ascertaining the death of a person and cognitive acceptance of the new situation; it starts the mourning process. Seeing the dead enables separation to take place. Uncertainty about the fate of the beloved impairs cognition, emotions and further functioning. The continuing ambiguity may lead to permanent trauma affecting the individuals and their communities (42).

This uncertainty creates a “state of unbearable hope” (46) amongst the family members that their beloved will come back. The distress and torment experienced by the relatives disturb their natural grieving process and psychological and social healing (43)(46).

In situations in which the recognition of the body is impossible, the DNA analysis of the remains and obtaining a match, provides the “evidence of death” so important to confirm the fate of the beloved. The succinct assertion has been made by Calacal and De Ungria (47) regarding the aftermath of Typhoon Sendong in the Philippines during 2011:

> “[t]he identification of the dead is not for the sake of the dead, but for the sake of the living.”

3.4 Societal value of identification

DNA methodology has been and is being made use of while identifying victims in numerous catastrophes, natural or man-made, since its employment as one of the established disaster victim identification methods. The number of examples described in the literature include incidents of fire, transportation accidents, terrorist attacks and mass war graves (32)(46). The inability to confirm the death of the person negatively affects not only the individuals and single families but it has a broader significance to the communities affected particularly by mass disasters and wars.

To include a wider, societal perspective this section delves into the value of identification of the dead and missing by DNA profiling that has inestimable importance not only to the individual but to entire communities. In order to illuminate the subject, a brief account of situations of multiple victims in mass disasters, wars and liberation struggles in different regions of the world is presented.

3.4.1 In disasters

Airplane crashes like the Spitsbergen crash in 1996, TWA flight 800 crash in 1996, Swissair Flight 111 crash in 1998 confirmed the significant role of DNA identification

in disasters where remains are fragmented. DNA analysis assured accurate identification of the victims when used as an exclusive identification tool or in combination with other methods (32) and established the importance and necessity of DNA profiling in disaster victim identification . The identification of the 156 victims in a cable car disaster in Kaprun, Austria in 2000 was largely relied on through genetic analysis (48). DNA profiling was employed following natural disasters like the Tsunami in Southeast Asia in 2004 and Hurricane Katrina in 2005 (32). In the Thailand Tsunami with approximately 230 000 victims molecular genetics had to play a secondary role due to severe decomposition of bodies resulting in degradation of DNA, rendering this technology non-functional (48).

An entirely different situation occurred following the September 11, 2001 terrorist attack in New York where DNA-based technology demonstrated its enormous value. The largest terrorist strike on US soil to date, gained worldwide attention not only due to is horrific nature and loss of lives of approximately 3000 victims but also for the extensive and most diligent recovery of the bodies and identification efforts. Human remains in the aftermath of the Twin Towers collapsing were severely fragmented and comingled, however, the existing capability of DNA profiling contributed to the identification of 59% of remains recovered, assuring the identification of 1626 victims (32).

According to Edson *et al* cited by Butler (32), the DNA analysis of the remains from the Pentagon Site and the United Airline Flight 93 crash site in Pennsylvania lead to the discovery of several male DNA profiles that did not positively match the reference samples provided for the presumed victims and which demonstrated Near Eastern lineage when tested with mitochondrial DNA. These were attributed to the hijackers confirming their ancestry corroborating the United States government version of the events.

3.4.2. In war and conflict

Many regions of the world have become infamous due to atrocities carried out during various armed conflicts, dictatorships and oppressive regimes. These crimes against humanity resulted in innumerable victims, the dead and the living; devastated survivors still awaiting amends and justice. These experiences have affected people

not only on the individual level but on the collective level as well, changing the existence of the communities as a whole (8)(49)(50).
This section examines how victim identification efforts in the post-conflict setting can provide for the redress and healing of the involved communities and societal groups, positively influencing the fractured lives of the surviving community members.

In this context the armed conflict in former Yugoslavia, the dictatorship in Argentina, the regime and wars in Iraq, and apartheid in South Africa stand out, as the respective communities were negatively affected on a large scale, battling for the tranquillity of reconciliation in the aftermath. Various victim identification projects were rolled out in these locations (36)(50)(51) engaging international organisations, forensic pathologists and forensic scientists from many countries. Many of the remains were exhumed and successfully identified permitting their return to their families.
The role that the forensic teams played in unearthing war and conflict graves in former Yugoslavia and in Latin America deserves to be highly prized. Rosenblatt (52) concisely summarised the violations that the victims buried in mass graves suffered on their bodies. These occurred while they were alive, when their lives were taken and also after death. These infractions involved three related facets: the identity of the deceased, the resting place of the deceased and the care which mourners provided to their dead. Identity can be progressively taken away from a person; first, by stripping them of their clothes and personal items and confiscating their identity documents; secondly, by disposing of the dead, unnamed, in mass graves and finally, as happened in Bosnia, by destroying the mass graves with bulldozers to make further identification impossible.

Similarly anyone, whose body has been disposed of in an isolated way, nameless and in an unknown place, is hurt not only in person but through the harm inflicted on the relatives who are unable to recover and bury their dead in a culturally appropriate manner. The value of identifying war and conflict victims for communities can be appreciated in depth, personally as a member of the identification team or through reading subsequent publications, while becoming familiar with the aftermath of specific conflicts. The following paragraphs briefly refer to Bosnia, Iraq and South Africa. The example of the search for the many missing in post-apartheid South Africa also brings attention to transitional justice mechanisms which assist in bringing

to an end the suffering of people affected by injustices of the oppressive former regime and ensure the restoration of the normality to relatives.

3.4.2.1 Bosnia

Haimes and Toom (50) offer an insight into the social value of identification while examining the complexities of kinship analysis during DNA profiling based on the case study of the Srebrenica massacre. The Srebrenica massacre took place in July 1995 during the Bosnian War, 1992-1995. Reportedly more than 8000 Muslim Bosniak men and boys were systematically killed by Bosnian Serb forces.

Due to the organized efforts in concealing these crimes by burying the bodies in the initial mass graves, exhuming and re-burial of the fragmented remains in the final mass graves the retrieval of these comingled remains after the war became a gruelling task. In 1997 the Physicians for Human Rights began the Srebrenica Identification Project. They faced numerous unidentified remains and a community longing for their missing relatives.

The identification of the missing, which is still ongoing, ensures better understanding of their last moments, burial according to the community rites and enabling the mourning process within the affected community to continue. The recognition of the identity of the victims re-establishes their individuality, humanity and gives an opportunity to commemorate the restoration of family ties and community links.

3.4.2.2 Iraq

In the last 25 years of the past century including the more recent armed conflicts in Iraq approximately 300 000 Iraqis disappeared in the context of arrests, imprisonment and executions (8). In the face of these enormous figures and severely restricted resources, the prospect of being able to find and identify any significant percentage of the remains and to return them to their awaiting families is gloomy as the goal is practically unobtainable. Cordner and Coupland (8) emphasize the sad reality that a large part of Iraq's population may never reconcile the past atrocities they fell victim to, if the missing cannot be found and identified.

Apart from having to deal with loss of shelter and support in their decimated communities, the families are torn by terrors of experiencing the uncertainty about the fate of their beloved. Stover *et al* (53) offer an insightful commentary on exhumations from mass graves in Iraq. The authors endorse the engagement of family members in observing the exhumations at the sites where they expect their relatives to be buried as this has a comforting effect in the appreciation of the efforts and care dedicated to the dead. Additionally, involving the families in gathering medical records of the missing to assist in identification may alleviate the overwhelming helplessness they feel. Exhumations conducted under the auspices of acclaimed institutions provide acknowledgement of their loss. This, together with collectively paying tribute to the victims, facilitates the grieving process at the community level.

3.4.2.3 South Africa

Regretfully, South Africa has its own share of history in the destruction of individual lives and community welfare by the crimes committed against human rights under the apartheid regime. Many anti-apartheid activists were killed by security forces, others fell victim to violent fighting between rival political factions.

In 1995 a very special and essential piece of legislation was introduced in the new South Africa, the Promotion of National Unity and Reconciliation Act (54), to facilitate the investigation of human rights violations that took place during the apartheid era. The Act's provisions include the establishment of "the fate or whereabouts of the victims" and

> "...The taking of measures aimed at the granting of reparation to and the rehabilitation and the restoration of the human and civil dignity of, victims of violation of human rights..." (54)

Based on this Act the Truth and Reconciliation Commission (TRC) was founded to promote social reconciliation in post-apartheid South Africa.
According to Aronson (10)(15) more than 2000 people are known to have disappeared or gone missing in South Africa during the apartheid period, mostly in the 1980s and early 1990s. The TRC however officially recognized 477. The inclusion criteria onto the list of the missing limited the official recognition to a strictly

political context. This excluded many of the unaccounted persons potentially causing resentment within the communities.
The Missing Persons Task Team was established within the National Prosecuting Authority in 2005 on recommendation of the Truth and Reconciliation Commission. Their efforts resulted in the successful identification of most of the located and exhumed remains; up to 2011 this was approximately 50. These remains were handed back to their respective families. The reconciliation process however was not free from problems in that instead of the feeling of resolution and forgiveness, it left part of the population with “anger and bitterness” (15).

Following investigations of human rights abuses during the apartheid era the human remains that have been traced and exhumed comprised mostly old skeletal elements which have been subjected to damage through burning and fragmentation. The Forensic DNA Laboratory in the Department of Biotechnology, University of Western Cape was entrusted with pioneering and further developing the DNA profiling programme to assist in the identification of the apartheid victims (36).

Several politically active adult men and teenagers from the township of Mamelodi near Pretoria became victims of apartheid when they were murdered by the security police in the late 1980s. They are recognised as the Mamelodi 4 and Mamelodi 10. The bodies of all 14 men were destroyed either by landmines or by fire. The remains were located in 2005 and DNA profiling was used for their identification, with partial success. The families, despite being able to bury the remains of 13 were disappointed in lack of recognition for their fallen men as military veterans (10).

On the examples of the Mamelodi victims, Aronson (10) relates that the recognition of the missing from the apartheid era by returning the remains to their relatives for burial, thanks to scientific advances in the identification the DNA profiling presently offers, was not sufficient to settle the pain and anguish they have been experiencing for many years. The families wanted an official recognition of their dead men as soldiers fallen in the struggle for the new liberated South Africa. To heal their wounds they wanted not only an identification of the nameless missing belonging to a family and community, they also wished for an official acknowledgement of the role they played in the abolishing of apartheid.

Aronson concludes that DNA technology assists in recognition of a biological identity however, it does not ensure the recognition of a social identity to the missing:

> "...DNA identification provides the *opportunity* to produce some sense of closure for families of the disappeared, rather than closure itself." (10)

In her paper, Krüger (55) paints a compelling picture of how the repatriation, restitution and burial of displaced mortal remains provides for tribute to ancestors and redress of colonial legacies.

Numerous skeletal remains of indigenous people of America and Africa are stored and displayed in museums in the United States and Europe, having been sourced into collections dating back to the19th century from their original places. There are approximately two thousand skeletons of "Bushmen" in South African musea. These unnamed remains, "bones of memory", have a great cultural value for the nations they came from as they incorporate their history. DNA profiling and archeological studies can prove their ancestry and aid in land restitution claims. The successful repatriation of Khoisan Klaas and Trooi Pienaar from Austria in 2012 and Sarah Baartmaan from France in 2002 was a symbolic celebration of heritage.

This chapter has highlighted the value of the identification of deceased persons for individuals and societal groups. Proper recognition of the dead is critical for legal and financial reasons, for appropriate burial of the remains according to observed traditions and proper closure for the relatives and communities. The value of DNA profiling in the identification process is that it restores the biological identity of unidentified remains and opens the way to closure for individuals, families and communities, and to reconciliation following armed conflicts and human rights abuses. Thus far this report has outlined the phases of the identification process including the molecular foundation of DNA profiling and the merits it offers for the individual families and entire communities in order to set the stage for further deliberations that will lead to the central points of this research. In order to later establish ethical standards for DNA identification processes the next chapter is dedicated to analysis of ethical concerns which surfaced following the inception of DNA methodology in identification.

CHAPTER 4: ETHICAL CONCERNS RELATED TO DNA IDENTIFICATION

4.1 Introduction

DNA analysis is widely accepted either as a principal or complementary method of identification of unidentified human remains despite being labour intensive and costly. The advantage of being able to identify even the smallest parts of remains has established it as a priority methodology when there is extensive fragmentation of corpses. DNA profiling has become routine in the United states for disaster victim identification and for military casualties (32).

Even though DNA analysis is invaluable as it was demonstrated in the previous chapter, there are numerous concerns regarding this technique, in terms of protection of privacy during storage of the samples, secondary uses of samples, obtained data, adequacy of consent, discrimination due to unequal racial representation on databases and limited access to DNA identification programmes for poor communities, to list a few. These concerns arose from problems that were encountered during identification efforts utilising DNA technology. As the methodology is relatively new and constantly developing, these observations and reports are quite recent. Some of the issues such as resource allocation in poor areas or racial issues in multiracial communities surfaced in specific incidents; other concerns are universal, such as questions of genetic privacy.

The complexity of the DNA identification process with all its multifaceted implications is visible, particularly in events with multiple victims where comparing numerous profiles has to take place.
During these incidents not infrequently mutilation of the bodies occurs with decomposition, fire destruction, fragmentation and comingling. On occasion there may be no intact DNA to obtain a full individual profile, partial or mixed profiles may only be achieved. For DNA profiling to be successful verifiable reference DNA samples are also needed from the victims and from the relatives. The preferred relationship in kinship matching is a first degree relationship (1)(32). Standard DNA testing with the short tandem repeat method on autosomal chromosomes may not be

sufficient and more complex methods using mitochondrial DNA or Y-chromosome may be necessary (32)(56). The non-standard techniques have their own technical limitations that need to be considered and solved (34). With large numbers of analyses performed the possibility of matches obtained by chance is greater than with routine testing (1).

This chapter offers a review of main concerns that relate to social and racial issues, disclosure of incidental findings, associated research and privacy protection and familial searching related to forensic databases. The notion of informed consent in the context of DNA identification is also examined. The following sections strive to demonstrate that these issues should be taken into account when procedures involving utilisation of DNA profiling are employed in identification of human remains. Paying attention to the bioethicists and other observers voicing their opinions on these matters and following their recommendations assists to prevent harm to the surviving relatives and community members.

4.2 Social issues

This section concerns social inequalities and economic discrimination particularly in cases involving numerous victims in combination with impoverished regions.

There were significant differences in the way the procedures of identification of the dead were handled in various disasters and in the aftermath of armed conflicts. The lack of efforts at identification of the dead from mass fatality in poorly developed regions contrasts with extended, brisk and effective identification procedures in events with fewer victims in well developed regions (8)(11)(45)(48).

The aftermath of the 2004 tsunami serves as a striking example (45). More than 175 000 people fell victim to this enormous natural disaster. Identification efforts were carried out in Thailand where there were large numbers of tourists, neglecting other affected regions. Most of the Asian victims were never identified before cremation or burial. In Sri Lanka a search for missing foreigners conducted by internationally founded and manned commissions included exhumations from mass graves.

According to Sumathipala *et al*:

> "The local poor had to suffer the indignity that their loved ones would be exhumed in order to identify a few tourists without proper DVI system in situ for Sri Lankans". (45)

Similarly, following the 2010 earthquake that devastated Haiti no significant help was offered to Haitians by the international investigators in contrast to recovery efforts of the remains of foreigners.

London *et al* (11) initiated calls for the formation of official international bodies that would ensure more equitable access to the scientific achievements of DNA methodologies and promote social trust in the DNA identification process.

Access to the identification process through DNA technology affords justice to the deceased and their families, and protects the economic and social rights of the relatives. All people should have equal access to the benefits science can offer without being discriminated against on the basis of their income or social status. All efforts should be made by the states and international organisations to make it possible.

The concerns regarding unequal racial and social representation within the forensic databases below are addressed in the section on databases.

4.3 Resource allocation

The main defining characteristic of a mass disaster is its magnitude which overwhelms the ability to cope and the need for external assistance as the local resources are usually insufficient to handle the situation (57). Large scale crises require careful assessment of the available resources and their just distribution.
A frequently asked question is the one of resource allocation for the management of the dead while survivors are in need (9)(47). In the manual "Management of dead bodies in disaster situations" (46) the Pan American Health Organisation (PAHO) lists the "recovery and management of bodies" as one of the fundamental actions required following a disaster together with rescuing of survivors and restoration of basic facilities. The Pan American Health Organisation (46) and International Committee of the Red Cross (1) recommendations in circumstances of limited

resources state that identification utilising DNA methodology should be performed as a last resort, when other methods of identification are not possible.

Another question being asked, particularly in situations of extensive fragmentation of bodies as in plane crashes (56) and, as happened during the collapse of the Twin Towers in 2011(32) is how much time and resources ought to be assigned to identification of the body fragments (56).
Should *all* fragments or fragments meeting predetermined size criteria be included in the DNA identification process? Is a re-association of *all* fragments of the remains necessary or is it sufficient to ascertain that the person died?

The experience informs that many of the relatives wish to reclaim even the smallest fragments of the tissues of their beloved (32)(56). One could argue for testing of *all recognisable* body fragments which subsequently would lead to more complete re-association of the remains to fulfil the needs of the families to recover and bury bodies in their entirety.

This approach would ultimately satisfy the bereaved relatives however when resources are scarce one has to be realistic and consider an equitable share in the benefit of identification for *all involved* families. It has to be borne in mind as well, that a confirmation of a number and identities of the dead is dictated by judicial requirements to establish death and that scientific grounds for the decision making exist.

The principles of good practice dictate that the decisions on the extent of the DNA profiling should be made based on the feasibility of obtaining good results from DNA matches (12) and on the degree of fragmentation (58). In order not waste precious resources, guidance from the experienced scientist should be sought in regard to the chances of obtaining good results from the particular methodology for the fragments while considering their size and state of preservation.

Having the above legislative and technical considerations in mind, the author supports the utilitarian principle of “greatest good for the greatest number” (12) when prioritisation in decision making is necessary in the face of resource limitations.

The identification of bodies in situations of multiple victims and in the setting of resources restricted by poverty is particularly challenging due to the complexity of the undertaking and associated costs. The utilisation of DNA methodology in mass fatality settings may just not be feasible due to being labour intensive, expensive and time consuming. Prioritising the needs and appropriate resource allocation may be a reality that has to be understood and included in mass disaster plans (46)(56).

However all possible attempts should be made to identify the dead, if this is not possible, they should be buried separately, not in mass graves. If common graves are unavoidable, the unidentified bodies must be buried in separate niches (46). This approach protects dignity of the deceased and facilitates future recovery and handing back the remains to the families safeguarding the rights of relatives.

The question of resource allocation arises when the demands are greater than available resources, particularly in situations of mass fatalities and in poverty stricken locations. DNA identification is a costly technology and in the protracted identification programmes consume large financial reserves and human resources. The reality of the need to prioritize within the DNA identification programme when the living survivors require attention must be taken into consideration. However if the situation allows, the dead should be identified with no efforts spared and appropriately taken care of to protect their dignity as well as for the sake of the survivors. The disparities in availability of resources for DNA identification could be alleviated by seeking international financial and laboratory support. The insensitivities to poorer local communities should be avoided not to increase their suffering.

Very fortunately, South Africa has never been affected by a mass disaster on a large scale which would prove severely testing for our local resources as it has in other parts of the world. One could be very concerned with the capacity of the biology units of the SAPS dealing with DNA profiling and their ability to handle identification of human remains during a disaster, particularly when reports of “overwhelming backlogs” at the SAPS Forensic Science Laboratory in Pretoria due to staff shortage reach media as happened in 2006 (59). Since, the local expertise, capacity of SAPS biology units and availability of DNA sampling kits seem to have improved sufficiently for adequate daily functioning of DNA identification programme for criminal justice purposes and for identification of unidentified bodies when the need arises. In times of increased demand, some additional help with DNA identification of unidentified

human remains could be obtained from forensic laboratories at universities. The Forensic DNA Laboratory at the University of Western Cape which established and develops the DNA profiling programme, assists in the investigation of human rights cases (36).

4.4 Incidental findings

This section provides an account of ethical issues related to findings generated during DNA profiling that are unintended, termed “incidental findings”.
A consideration is given to the management of discoveries made during kinship analysis to facilitate ethical decision making in this regard.

DNA analysis compares the DNA sample from the deceased to DNA samples left while still alive in “direct matching” or when such sample is not available, to the sample obtained from the living relatives in “kinship matching”(4).
The kinship analysis is based on a calculation of probability of biological association between the deceased and putative close family members. This method requires valid reference samples from the next of kin (32) and does not discriminate well between profiles of several close relatives, particularly of the same sex (35)(36)(56). DNA samples for kinship matching and for the validation of family relationships are obtained from family members and analysed with consideration to perceived family links. This type of analysis can discover the absence of or only partial biological relationship between tested relatives. Additional samples may be required from other relatives.

According to Parker *et al* (4) the most common incidental findings in this context are discrepancies in relationships between siblings who may not be biologically related at all or only through one parent. Less common are discoveries of lack of genetic relationship between the father and the child. Divulging these unplanned findings to the donors of DNA samples may have a detrimental effect on family relationships. The scientists dealing with the identification process using DNA may be faced with a dilemma when these incidental findings are discovered. They need to make a decision between truthfully informing the relatives of these unintended findings or hiding the truth when, expectedly, the relatives ask why additional samples are needed.

Parker *et al* (4) provide compelling arguments for non-disclosure of these incidental findings based on principles of fair balance between risks of participation in the identification programme and benefits that this program offers to the families. Taking part in DNA-led identification efforts carries risks that differ in gravity for different participating individuals. Benefits of the DNA identification programme to a family depend on motivation of various individuals to join the program despite the associated risks. The risk of uncovering the relationship mismatches is unevenly distributed within the community; it is greater for women and in particular social settings where adoption or extramarital relationships are unacceptable. The policy of nondisclosure of incidental findings would minimise the potential harms to the relatives and make them more eager to participate. The strategy of nondisclosure makes the benefits of participation in the program available to more families and also to vulnerable groups that otherwise would not get involved and share the benefits out of fear of some private information coming out. Nondisclosure also ensures these findings discovered by chance are not misused. These considerations should find their reflection in the formulation of the consent for participation in the DNA identification programme and related policies.

Apart from fearing the discovery of discrepancies in genetic relationships between family members, there are concerns regarding unintentionally uncovering latent health issues of the donors from their DNA profile. Reportedly no genetic characteristics or health information can be found in a digital DNA profile (1)(3)(5), however this is questionable in view of new developments (16)(60) where some of the markers employed in DNA profiling have potential to predict eye and hair colour, sex, ancestry and relatedness and may reveal genetic abnormalities.

There is potential to uncover some very personal but non-genetic information about the deceased and the relatives during the identification process. Finding the remains in a specific place may reveal particular places visited and the fact that the deceased belonged to a group or community engaged in a certain activity, particularly obvious in the context of political conflict (4).The concerns regarding genetic privacy are further discussed in the section on forensic databases below.

4.5 Research

The research on humans is to be conducted with consideration to the rights and protection of the welfare of research subjects. The Belmont Report (61) provides an outline of the fundamental ethical principles that should guide the conduct of research on human subjects: respect for persons, beneficence and justice (62).

In the context of the theme of this work, the focus of the report is on possible secondary uses of DNA samples collected in highly traumatic situations as presented by incidents with multiple victims. The question that is posed when considering research in such settings is, what kind of research is permissible during the DNA identification process and if it is ethically justifiable (12).
All general principles governing research on human subjects are applicable to vulnerable groups (7).

The permission to conduct research on the biological samples collected from legally incompetent deceased individuals requires explicit consent from the authorized representatives and strict protection of privacy and confidentiality by anonimising samples and genetic data. Obtaining consent during times of disaster for uncertain future research from the relatives whose consenting capability is affected by severe emotional distress is not ethically acceptable and is harmful for the research itself, as it undermines public trust in the data gathering process.
Knoppers *et al* (7) propose that in respect of samples collected during disasters primarily for identification, the morally permissible research must advance the technology designed for the purpose of DNA identification and ultimately must benefit the affected community. Being advantageous to the community, fulfilling community expectations and keeping within the parameters of original consent for identification provides justification for secondary use of human biological material.

There are no legislative provisions in the DNA Act (22) for conducting research. No reference is made to any type of research in the 2015/2016 Annual Report (63)(64) of the National Forensic Oversight and Ethics Board. The “DNA Board” was established under the DNA Act for the purpose of oversight of implementation of DNA Act provisions. The functions of the DNA Board are described in more detail in chapter 6 of this research report. The research that is conducted in the Forensic DNA Laboratory at the University of the Western Cape aims to develop novel technologies

and advance the existing technology applicable to forensic cases. The work of the Laboratory is very useful for South Africa as it concentrates on developing markers polymorphic for the South African population and to create a large database that can be reliably used for the calculation of a “match” probability (36).

4.6 Informed consent

This section deals with the notion of informed consent in respect of DNA identification procedures.

The International Committee of the Red Cross (ICRC) guide titled “Missing people, DNA analysis and identification of human remains” (1) addresses the DNA identification process in armed conflict and armed violence situations and clearly sets down standards to follow when biological samples are used in the creation of DNA profiles, including the related consent.
ICRC prescribes, that samples for DNA analysis may be obtained and tested only with the informed consent of the donor relatives. The process of informed consent is to ensure the relatives have an informed understanding of the reasons for collection of the samples, the expected benefits of participation, the functioning of the programme, the protection of the genetic data, the release of information and the format of the consent. The full explanation with emphasis on voluntary participation is to guard against family members being coerced to participate in the identification programme against their will.

Parker *et al* (4) discuss informed consent in the context of incidental findings that are uncovered during identification efforts. The authors stress the importance of disclosing the possibility of incidental findings of a genetic and non-genetic nature during the identification process to the relatives so they can make informed choices whether to participate or not. The way of dealing with these unintended findings, and they convincingly argue for a policy of nondisclosure, should be clearly determined before or during the stage of obtaining consent for participation in the DNA identification program. The preferred policy of nondisclosure and all significant matters relating to safeguarding of incidental findings should be sufficiently explained while obtaining consent and addressed on the consent form.

4.7 Forensic databases

This section discusses ethical issues associated with use of the samples and related data in forensic databases. The concerns relate to genetic privacy, familial searching and undue racial discrimination by skewed representation of certain racial groups in mixed race societies (5)(6)(13)(65). The advantage of separation of missing persons database from the criminal database is demonstrated on the example of Spain.

The local forensic database, the National Forensic DNA Database of South Africa is a combination of criminal, missing persons and unidentified human remains cases. Further reference to the National Forensic DNA Database of South Africa is made in the sections below and in chapter 6 of this research report.

4.7.1 Personal data

The advances in DNA technology, not readily understood by laymen, cause apprehension within communities and wide fears of invasion of privacy.
According to Keating *et al* (60), the capacity for predicting the bio-geographical ancestry, sex, hair and eye colour, and familial relatedness already exist using ever developing molecular assays and genetic markers. These non-standard sets of DNA markers developed and validated for the budding field of “DNA intelligence” (60) are available as commercial kits.
Although these tools are potentially invaluable in identification of criminals and missing persons, their utilisation is in contradiction of the right to protection of genetic privacy and their further evolution is difficult to comprehend and predict fully.

The potentially harmful implications of acquiring sensitive genetic information have been appreciated for some time already. As cited in the International Committee of the Red Cross (ICRC) guide on identification in the context of armed conflicts and violence (1), the United Nations Educational Scientific and Cultural Organisation (UNESCO) 2003 International Declaration on Human Genetic Data asserts that “human genetic data have a special status” because it carries sensitive biological information of cultural significance to individuals and communities. Following the UNESCO’s 2003 Declaration, the ICRC’s guide emphasise that genetic privacy should be offered strict protection and that “collection, processing, use and storage of

human genetic data" (1) should be in accordance with international human rights and national laws.

The integrity of the genetic data stored on the National Forensic DNA Database of South Africa is protected by access being limited to accredited persons and the location being equipped with biometric security and cameras (64). No security breach or errors of accidental removal of the stored profiles were reported in the 2015/2016 Annual Report (63). The Biology Unit of the SAPS Forensic Science Laboratory observes strict protocols under the quality assurance programme to assure the appropriate standards of case work are met (19).

The potential of the discovery of confidential health problems during DNA testing (5), causes a lot of misgivings about DNA technology. Revealing tendency to certain diseases may cause difficulties in obtaining life policies or introduce exclusion conditions. Similarly, there may be a selection bias during recruitment for certain employment positions. The fear of uncovering a predilection to certain medical conditions may not be completely unfounded since certain aspects of DNA profile may indicate chromosomal abnormalities (16).

4.7.2 Familial searching

Searching through databases for close DNA sequence matches, called 'familial searching", yields a number of genetically related individuals. In a criminal database context, it broadens the "persons of interest" group leading to investigation by police of the individuals being close genetic matches. This may lead to stigma and shaming of the individual in the community when the biological relation, perhaps even unknown previously, to the suspect in a criminal case, is uncovered and the information leaked out (5). In multiracial societies where some of the ethnic groups may be more represented on the criminal databases, familial searching may single them out for societal rejection and criminal prosecution (6).

A very concerning possibility is the utilisation of the data stored in criminal databases to support behavioural genetics. This identifies genetic predispositions to violent behaviour with the subsequent founding of some kind of surveillance programme over the public and identifying children at risk of aggression. This would possibly lead

to behavioural modification methods and even prenatal selection or gene therapy for the affected individuals (5).

Familial searching has a potential to open the individuals on the forensic database to violation of genetic privacy together with discrimination and stigmatisation of individuals and societal groups. Familial searching, while being useful in identification of missing persons, due to these problems, should be under strict ethical oversight to prevent human rights abuses. In the context of this study, references regarding familial searching need to be included in the final recommendations.

According to the 2015/2016 Annual Report, at present no software with capacity for familial searches is available to be employed in relation to missing persons on the National Forensic DNA Database of South Africa. Furthermore, policy addressing familial searching and the related software are still to be implemented (63).

4.7.3 Missing persons database

A number of countries have been developing their forensic databases as a crime-combating tool, while others created non-criminal databases with missing persons in mind (66).

The world's first database for the purpose of identifying missing persons was set up in Spain at the beginning of the last decade. This database was reported to operate successfully under provisions of strict control and voluntary donation of DNA samples by family members searching for their relatives. This genetic database comprises two mitochondrial DNA catalogues, one containing references from the maternal relatives, the other being a collection of genetic sequences of the deceased to be identified. Informed consent and the voluntary participation from the donors ensures that social and individual rights are not violated by operating this civil database (66).

The forensic databases in South Africa are discussed in chapter 6 of this research report dedicated to an ethical assessment of the local laws, specifically the DNA Act (22).

4.8 Concluding remarks

The discussion in this chapter is focused on a number of concerns that exist regarding DNA identification. These concerns relate to economic and racial discrimination, resource allocation, secondary uses of samples and data collected for identification and the protection of genetic privacy.

Economic impoverishment reduces access to identification efforts particularly in situations of multiple fatalities, this infringes on the right of the families to just use of scientific advances. Limitation of resources is most pronounced in large scale disasters which may impose strict prioritisation rules favouring the needs of survivors however no efforts should be spared to appropriately care for the dead, including their identification to protect their dignity and the rights of the surviving relatives.

Policies regarding the extent of DNA identification procedures in case of increased demand during mass fatality situations and policies dealing with incidental findings need to be established at the outset of the DNA identification programme. A favoured policy of nondisclosure of incidental findings is ethically justifiable.

Full explanation regarding the rules of participation in the DNA identification programme is to be provided to the interested relatives before collecting reference DNA samples. Comprehensive informed consent is required to ensure that the family members have sufficient understanding of the principles of the DNA identification processes and enter the program on an absolutely voluntary basis.

Research which can be ethically justified in a disaster situation must advance the DNA methodology for the purpose of identification and benefit and fulfil the expectation of the affected community.

Forensic criminal databases are common objects of discussions as a source of ethical concerns. Familial searching exposes many individuals to criminal investigation based on close genetic matching. In multiracial societies there may be unequal representation of certain ethnic groups on the forensic databases exposing some of the communities to stigmatisation in connection with criminal investigations.

Keeping the missing persons databases separate from criminal forensic databases would be a step in the direction of improving public trust in the identification efforts.

The missing person database in Spain, operating on ethical principles similar to medical databases, has achieved great success.

Future developments in DNA technology are difficult to predict, at present a cause of concern is the invasion of privacy. Some of these fears are not without basis. The emergence of “DNA intelligence” with specialised tools to predict appearance, sex, ancestry and kinship, on one hand appears useful for identification of unidentified human remains, on the other hand seems to be quite concerning from the point of view of genetic privacy, if misused. Potential exits to reveal chromosomal abnormalities with standard DNA profiling kits available commercially and used in South Africa.

The complexity of DNA identification, sensitive nature of biological samples and genetic data which are stored on the forensic databases poses a potential danger for human rights violations and requires meticulous protection. Revision of existing ethical concerns presented in this chapter serves as an introduction to identify basic ethical standards that should be applied in DNA identification programmes relating to human remains. On this basis a set of fundamental ethical principles to guide DNA identification efforts is formulated in the next chapter.

CHAPTER 5: ETHICAL STANDARDS FOR DNA IDENTIFICATION

5.1 Introduction

The role of this chapter is to create a set of ethical standards that provide a solid framework for decision making in the identification of unidentified human remains utilising the DNA methodology. A set of ethical norms that applies to DNA identification may be derived from the recognised ethical principles (1)(67), from the ethical analysis of previous events and disasters (9)(11)(45) and where bioethicists have raised their concerns and proposed ethically valid solutions (4)(5)(7)(12)(16).

In the next chapter of this work a set of ethical principles will be employed as a standard to measure the application of ethics in relation to South Africa's legislation specifically designed to embrace the DNA methodology in identification of persons, the DNA Act. In the last chapter this scaffold of morally sound norms will enable the creation of stable and reliable guidelines to be followed when dealing with the DNA identification procedures.

As intended, this chapter presents an argument that morally and legally justifiable ethical norms and well implemented laws on DNA identification are a necessity. This task is achieved by:

a) Identifying the basic ethical principles that ensure the DNA identification procedures are morally permissible and
b) Validating these standards by showing their key role in ethically valid and responsible decision making.

5.2 Humanitarian aspects

When confronted with unidentified human remains the stakeholders involved in identification are met with a challenge of fulfilling their professional duty toward the deceased while dealing with the bereaved family members. The family members are distraught and anxious to find out the fate of their missing relative. The officials who have direct contact with the families are police officers and staff members of the

forensic mortuaries and in the case of mass fatality there may be other members of the response team including grief counsellors, community liaison officers, clerics and spiritual advisors.

The following sections contain a brief discussion on the importance of a sympathetic and caring attitude toward the family members who are in great distress looking for their missing relatives and appropriate timing for providing families with information.

5.2.1 Compassion and humanism

The stressful circumstances of the identification process including the DNA methodology, dictate a compassionate and humane approach to the relatives living through their tragedy of loss of a loved one. The first-hand experiences of the bereaved can be found in the reports of the family members (43) published on the website of Disaster Action, the United Kingdom based charity with members who have been personally affected by a number of terrorist attacks, transportation accidents and natural disasters. These accounts contain negative examples that left long lasting negative impressions upon the families regarding the process of identification. There are also instances of good practice, which receive praise. These reports illustrate the need for empathy, accurate reporting which needs to be regularly repeated to families due to diminished capacity to absorb information during severe stress, respect for the families and thorough sensitive preparation before viewing of the bodies, particularly if the bodies have been affected visually.

Humanity is the leading principle of the seven fundamental principles of the International Federation of Red Cross (IFRC), the multinational humanitarian organisation upholding human dignity and relentlessly fighting against human suffering (68). The goal of the identification process is to provide relief from the emotional suffering experienced by family members and should not provoke any further pain and frustration. The family members tormented by uncertainty about their beloved appreciate tactful and caring conduct of the personnel they come in contact with.

According to Eyre's (41) compelling report on survivors' needs in emergency situations, in the event of a disaster the "care, concern and understanding" received

from the disaster workers have a protective effect on the persons affected, while lack of adequate social and emotional support, and an impersonal manner are risk factors for negative psychological outcomes in survivors.

It is important to address the needs of the relatives as expeditiously as possible in the given situation. Any prolongation of the identification process including a delay in the viewing of the deceased bodies causes “great upset” (41) and should be avoided whenever possible.

5.2.2 Notification of family members

Relatives frequently search for their loved ones anxiously to either find them well or confirm the worst. Well-timed, clear and as far as possible complete, communication of the facts to relatives alleviates their mental anguish. Particularly in situations of mass fatalities the distribution of “regular and appropriate information” is much welcomed by the anxious relatives while lack of appropriate information causes their “frustration and anger” and contributes to prolonged and more severe traumatic reactions (41).

5.3 Universal ethical principles

The organisation that deals with main bioethical issues within the field of biomedical sciences at the global level is the United Nations Educational Scientific and Cultural Organisation (UNESCO) with its International Bioethics Committee. The bioethical framework advocated by UNESCO in the 2005 Universal Declaration on Bioethics and Human Rights (67) derives from the endorsement of human rights. The 2005 Universal Declaration comprises a set of fundamental bioethical principles to guide ethically justifiable actions that apply to DNA-utilising technologies amongst other biosciences. The principles outlined in the Universal Declaration are multidimensional and interrelate with each other.

A well established ethical framework that rests on the authority of the reputable international organisation promotes “respect for human dignity and protects human

rights” (67) and commands acknowledgment while formulating the laws and policies on the use of DNA in identification.

The paragraphs below reflect on application of these truly universal ethical norms in the management of the DNA identification process and advocate that they should be implemented through laws and related policies.

5.3.1 Human dignity and human rights

The concepts of dignity and human rights constitute a primary vision that serves as an inspiration to all derived ideas. In accordance with article 3 of the UNESCO’s 2005 Universal Declaration “the human dignity, human rights...are to be fully respected”. (67) In this section, from the perspective of reverence of this principle the author reflects on the concepts of human rights of the dead and the human rights of the living who mourn their beloved.

5.3.1.1 The dignity and rights of the dead

Few authors bring up the interests and rights of the dead in the context of humanitarian action (9)(52)(69).

Analysing the existing publications on the dead as the rights-holders Bagherzadeh (9) asserts that the concept of human rights of the dead plays no significant role in the management of dead bodies after disasters as the dead are not capable of claiming their rights and interests on their own. This neither negates the need for the respect of the dead nor erases human rights violations if they occurred at the time of death. The idea of responsibilities toward the dead dictates certain respectful ways in which bodies should be handled; the dead are to be honoured by proper burial and commemoration. These responsibilities are born of the dignity the dead have and from the respect they deserve. The dignity of the dead embodies the human life that once was.

De Baets, cited by Bagherzadeh (9), in the Declaration on the Responsibilities of Present Generations toward Past Generations, indicates the identification of the body as one of the key responsibilities of the living toward their dead.

The belief that the living have responsibilities toward their dead appears more practical where management of dead bodies is concerned (9). It allows for the living who are capable of action to oblige and provide for the dead, to recognise and honour them. Any violations concerning the fulfilment of the responsibilities of the bereaved to their dead do not remain silent.

5.3.1.2 The rights of the bereaved

Under international human rights law and international humanitarian law the bereaved have a right to know the fate of their missing relatives and receive their remains (70) in order to fulfil their responsibilities toward them in a dignified manner. Unearthing of post-conflict mass graves serves this purpose, however the goals of these efforts may be clouded by prioritizing the evidence gathering for criminal trials, as happened in former Yugoslavia, rather than considering the interests of the survivors (52). The hastily manner in which exhumations of mass graves were carried out during 1990s for the purposes of International Criminal Tribunal, did not satisfy the needs of the bereaved families for respectful treatment of the remains and their identification. Subsequently, the International Commission on Missing Persons was established and an extensive victim identification project was rolled out.

In accordance with a rights-based approach there is a strong inclination to provide increased attention to the wishes and needs of the grieving families. This trend has been driven by the families who experienced appalling treatment in the aftermath of some disasters (41). The same considerations apply to individual cases as to the situations with multiple victims.

The psychological recovery process of survivors is positively influenced by the appropriate handling of bodies including their viewing, honest information regarding the recovery, being provided access to the post mortem information, being able to decide on the further handling of the deceased's property and facilitating visitations to the incident site.

De Baets, cited by Bagherzadeh, in the Declaration of the Responsibilities of Present Generations toward Past Generations includes the following important rights of the bereaved:

> “To mourn, to hold funerals, to bury and cremate and to commemorate” and to know the truth about past human rights abuses”. (9)

Disaster Action formulated a code of practice (71) aimed at the protection of “the rights and interests” of the bereaved and survivors of disasters. The guidelines in this code relate to privacy, confidentiality and consent. The code advocates guarding against potential harms to survivors, a fair balance between granting the relatives access to the information and preventing their intrusion as well as promoting awareness of relevant laws. The concepts of consent, privacy and confidentiality, so important for the DNA-based identification method are discussed in more detail in the following sections.

5.3.2 Benefit and harm

Article 4 of UNESCO’s 2005 Universal Declaration proposes: “direct and indirect benefits...should be maximized and any possible harm...should be minimized”. (67) This line of reasoning sets the scene for the discussion on the need to balance the benefits of DNA identification efforts with potential harms; ideally the benefits should outweigh the risks of participation.

A humanitarian purpose in identification efforts, including the DNA methodology, is served by recognition of the unidentified dead, letting the family know the fate of the missing person and enabling the relatives to conduct culturally appropriate funerals (4). Successful identification of a body which cannot be identified by other circumstantial or scientific means facilitates the grieving process and helps settle psychological trauma associated with death of a loved one. Identification aids in resolution of legal issues related to dissolution of marriage and winding up of the estate and allows for due financial compensation.

On a community level, the recognition of the victims of violence facilitates reconciliation and criminal prosecution, particularly when there has been a violation of human rights.
In instances of natural disasters and transportation accidents the identification promotes individual and community interests, in the ways as discussed above and also by addressing accountability. The benefits have to be clearly prioritized to eliminate any potential conflicts (4).

The risks of participation in the identification programme are diverse and depend on the situation of the individual and political climate. The characteristics of the DNA identification methodology, the cultural setting and social and political context influence the likelihood, extent and distribution of the risks (4). Vulnerable groups including women and the poor are at increased risk of harm.

Detection of misattributed paternity or lack of genetic linkage during DNA matching may cause serious consequences for the family when an extramarital affair or adoption is discovered. In traditional cultures, having a biological child of another man may cause rejection of both, the wife and the child, by the husband. In an unstable political situation, one may be singled out for participating in the identification programme related to investigation of past crimes when the ruling government changes again.

Careful formulation of the policies minimizing particular risks should aim to strike a positive balance between the benefits sought and unwanted potential harms. For instance, a policy of non-disclosure of genetic and non-genetic incidental findings to participants of the identification efforts can prevent potential negative effects on the family unit.

5.3.3 Autonomy

Autonomy in the perspective of article 5 of UNESCO's 2005 Universal Declaration (67) means respect for independent decision making and protection of the interests of the individuals who are not competent do so.

The autonomy of the family members is expressed by making an informed decision on the viewing of the deceased relative body. The viewing of the body confirms the death and provides an opportunity to start the grieving process. If the body is not viewed, the process may be delayed or certainty of death for the relatives may never take place. Even in instances, where out of compassion bodies are thought to be unsuitable for viewing, the decision to view should be facilitated but left to the individual to make. Preventing the relatives from viewing has a negative impact on their well being (41)(72)(73).

The family members can also exercise their right to autonomy by choosing, if they wish, to receive updates on the recovery process of the remains, particularly if it happens to be over a prolonged period of time (41)(72).
Since reclaiming the personal effects of the deceased is very traumatic the bereaved should be left to make their own choice in regard to the way the property is returned to them (41).

5.3.4 Consent

Logically, in article 6 of the UNESCO's 2005 Universal Declaration (67), the principle of respect for autonomy is followed by the principle of free and informed consent for medical interventions of any nature and research.

ICRC (1) determines the requirements for informed consent while collecting DNA samples from the living relatives of the missing. Consent is regarded as *informed* when an individual has an understanding of particular aspects relating to gathering of their sample. This includes understanding the purpose of sample collection, the procedures of the identification programme including the practical aspects, understanding how the process works and what happens with their sample. The participant must have an understanding of the likely benefits and risks of participation. It is also necessary for them to understand the principles of data management and use conforming to data protection rules and how this relates to their sample, how any gathered information may be disseminated and under what conditions. They must understand that consent is entirely on a voluntary basis and can be withdrawn at any time without having to provide a reason for doing so. The participant must understand the consent form itself and receive contact details to the appropriate person dealing with their sample.
These standards of informed consent safeguard against coercion into participation in the programme (1).

5.3.5 Respect for vulnerability

In accordance with article 8 of the UNESCO's 2005 Universal Declaration (67), Knoppers *et al* (7) classify the deceased persons in the "vulnerable" category due to their inability to protect their best interest, together with incompetent adults and

children. In the context of research the vulnerable have a right to be protected. As it was discussed in the previous chapter, the authors (7) hold the position that morally permissible research is that which serves in the development of DNA technology for the purpose of identification while at the same time benefitting the affected community. Ignoring the ethical considerations and conducting research on the samples obtained from the living relatives and from the deceased victims without an appropriate consent “infringes the dignity, autonomy and privacy of research participants”. (7) This kind of conduct may contribute to mistrust in communities and the failure of such valuable research on DNA methodology in the future.

When participation of the vulnerable living such as children and mentally incompetent is unavoidable in the identification process they require special attention and a considerate approach. Children may show excessive traumatic reactions in difficult situations especially when separated from their parents and will require the appropriate specialist support (41).

5.3.6 Privacy and confidentiality

Article 9 of the UNESCO’s 2005 Universal Declaration (67) emphasises respect for privacy of individuals and confidentiality of their personal information.
The unique character of the DNA molecule entails sensitive genetic information which demands strict protection of access to the samples carrying the DNA material and results of the DNA profiling. Reportedly, the standard short tandem repeat (STR) test cannot reveal genetic predisposition (1) that may be potentially used as a tool for discrimination or stigmatization. The UNESCO’s 2003 International Declaration on Human Genetic Data that underscored the special status of genetic data and specifically addressed genetic privacy issues was replaced by UNESCO’s 2005 Universal Declaration (67).
The ICRC 2009 manual titled “Missing people, DNA analysis and identification of human remains” (1) contains a list of commonly accepted ethical norms for guidance on the safeguarding of DNA samples and DNA profiling results. Of note are two rules: that the DNA profiling is to be reserved to instances where other methods of identification are unsuitable and that DNA testing without consent may be performed exclusively for identification purpose of human remains.

5.3.7 Equality, justice, equity

This principle expressed in article 10 of the UNESCO's 2005 Universal Declaration rests on the assertion that human beings are equal in dignity and rights and are to be "treated justly and equitably". (67)
Developed countries keep up with scientific advances of DNA identification technology and are able to allocate adequate resources for the DNA identification process when the need arises as was evidenced by an enormous identification programme established after September 11, 20011 (74). Contrasting circumstances exist in poor countries stricken by natural disasters. The principle of distributive justice may be satisfied when international organisations salvage the situation providing material help. The ethical guidelines in DNA identification programmes must address the need for prioritization if necessary.

Scarce resources limited the efforts of body recovery from mass graves that followed armed conflicts. The main goal of identification of the maximal number of victims was not achieved due to lack of resources (49)(52).
The establishing of the cause of death patterns important to criminal prosecution took priority over the interests of the surviving family members and many of the exhumed bodies were re-buried, unidentified. This was due to the DNA identification process being costly, time and manpower consuming as well as separate from forensic examination. Putting interests of criminal justice above the interests and rights of the individuals prevented the bereaved families from receiving their relatives bodies and laying them to rest (49).
Iraq, with the disastrous numbers of missing people during the Hussein regime and conflicts, can serve as a further example of resources limiting justice. Cordner and Coupland (8) describe the pitiful reality of inadequate resources which prevents the satisfactory solving the fate of the missing. They conclude that the bereaved are also victims of Iraq's history and will never heal from their losses.

5.3.8 Non-discrimination and non-stigmatisation

Conforming to article 11 of the UNESCO's 2005 Universal Declaration no discrimination violating human dignity or human rights on any grounds is permissible (67). This principle may be violated in instances of unjustified restriction of access to

the identification programme or, as it is the case with the United Kingdom National DNA Database (5), where the entries obtained during DNA testing for familial searching and research have been used for unintended purposes.

5.3.9 Respect for cultural diversity and pluralism

Cultural diversity, according to article 12 of the UNESCO's 2005 Universal Declaration is to be given due consideration providing this does not contravene or limit any of the principles outlined in the Declaration including the respect for "human dignity, human rights and fundamental freedoms". (67)
There is a duty on the state to protect the religious freedoms and cultural customs of the diverse population groups. In disaster settings, the related rights may be violated if the authorities do not respect the religious and cultural needs of the affected communities (46).

5.4 Meeting the standards

The scale of an incident where the identification of the human remains is required may affect meeting the established standards. The identification efforts using the DNA methodology sufficient for the ordinary case load may not adequately keep up with the increased needs. Despite the drive to identify even the smallest body parts (56), in cases where great fragmentation of the bodies took place, thoughtful decisions need to be made in regard to the size of the fragments to be tested. Severe fragmentation may require large numbers of samples to be analyzed, increasing the costs of identification (12).

In continuation of the theme of resource limitation from the earlier section, the reasoning in Cordner and Coupland's (8) paper is acknowledged. A sad but realistic contention of the authors commenting on the Iraqi circumstances is that "lowering standards of practice may be compatible with ethical practice" (8); this would be the case where even the most humble objectives do not withstand the severely constrained reality.

5.5 Concluding remarks

Due to the special character of DNA, the DNA-based procedures create a real ethical minefield for the personnel who are unaware of or unfamiliar with the specific related issues. The concerns include privacy protection issues, secondary use of samples, sufficiency of consent, discrimination against certain racial or societal groups and less open access to DNA-based identification programmes for communities that are poor. The risk of possible harms should be minimised by well considered and relevant legislation and observation of well established ethical and human rights standards where the DNA technology is employed. This research report aims to offer some resolution by formulating recommendations that should establish and direct ethical practices. These recommendations are listed in the final chapter and conclude this work. In this chapter the basic ethical values to serve as guiding principles for DNA-led identification programme were outlined.

Having a well thought out and comprehensive set of guiding ethical standards that mirrors the UNESCO's universal principles (67) drawn from human rights and standing for human dignity and freedoms, affords crucial protection for anyone participating in a small and large scale DNA identification programme. Following these ethical norms, when combined with a caring and kind attitude when dealing with the distraught relatives, will reduce negative psychological effects.

When there is an established set of principles to follow, the uncertainties on how to act or dilemmas arising in relation to the procedures are less difficult to overcome as there are established and accepted guiding principles. Acting in accordance with the recognised norms eliminates non-ethical behaviour and minimises the risks for participating relatives (4).

Sometimes a successful identification relying on DNA methodology may require a prolonged period of time. In individual cases and particularly in mass fatality situations, a humane approach to the bereaved and programme that runs within the ethical framework will provide the expected relief.

Any concerns that are not addressed will cause anger, mistrust and rejection of the identification effort while respect for the individuals and communities together with transparency will promote understanding and favourable reception from the families (15).

Public support for the DNA identification project will ensure a wide voluntary participation from the community and virtually guarantee the fulfilment of the essential role of the programme competently and benevolently. The example is a civil missing persons' database in Spain that is run on the principle of voluntary sample donation and informed consent (66). The opposite may be said about criminal databases where non-voluntary participation is enforced by law, in such cases human rights concerns cast a shadow on their functioning (5).

When faced with severe constraints the DNA identification programme may be tailored according to available resources. In desperate situations lowering of standards is ethically justified (8).

Even with progress of technological advances there are limitations on DNA identification processes that reduce its potential to identify human remains when genetic material is degraded as maybe the case with decomposition, old and burnt skeletal remains. In these cases the science may fail the expectant family members who hoped to be able to bury their loved ones. The inability of DNA profiling to individually identify the Mamelodi 10 was a great disappointment to their families. They were at peace with collective burial and they understood the technical difficulties caused by destruction of the remains due to fire and were closely involved in the whole process of identity restoration. The families wished for official recognition of their deceased service to the fight for freedom.
Many families of the missing from the apartheid era were let down due to a greater focus in recovery of the remains afforded to political figures than some ordinary people (15).
This shows how even a limited achievement of the science can bring solace to mourning relatives when other processes satisfy the emotional needs of the families and the deceased receive the expected social recognition. On the occasions when technology can be or is successful but other processes fail, the painful emotions are not consoled and the proper healing process is thwarted.

The above discussion demonstrates that the commitment to ethical conduct is essential when undertaking the identification of human remains using the DNA methodology. This offers a protection not only for the participating individuals,

families and communities but also safeguards the goal of the identification process, a dignified recognition of the deceased by attributing his or her name to the remains.

Strict adherence to ethical norms needs to be observed and reinforced by local and international laws that are in line with modern human rights approaches and are ultimately protective. There is a need to supervise compliance. Therefore it is necessary that ethical committees be established to deal with arising ethical issues. At a national level, in order to fulfil the function of safeguarding the fundamental ethical norms and human rights, statutes need to be well designed and furthermore, well implemented.

The next chapter will analyse if South Africa's laws applicable to DNA identification process can withstand scrutiny against the ethical principles that have been identified in this chapter. The ethical guidelines and policy recommendations follow in the last chapter.

CHAPTER 6: ETHICAL ASSESSMENT OF THE EXISTING LAW ON DNA IDENTIFICATION IN SOUTH AFRICA

6.1 Introduction

In the previous chapter the moral principles that should guide utilization of DNA methodology for identification of unidentified human remains were ascertained. It was demonstrated that a strong ethical framework to the process with support of well designed and implemented laws provides for good functioning of the DNA identification programme. To provide the backdrop for the ethical analysis of the law in South Africa this section recaps the set of ethical principles which were formulated previously.

The standards to guide the use of DNA in identification must follow basic humanitarian and human rights values. They should uphold the dignity of both, the deceased and the bereaved and express human rights of the living. A code of fundamental ethical norms which resonates with the universal principles contained in the 2005 UNESCO's Universal Declaration on Bioethics and Human Rights will effectively protect the ethical integrity of the DNA identification programme.

The following ethical principles were identified in order to guide conduct of personnel involved in DNA identification of human remains:

i. Respect for human dignity and human rights
ii. Respect for autonomy
iii. Informed consent
iv. Respect for vulnerability
v. Respect for privacy and confidentiality
vi. Equality and justice
vii. Non-discrimination and non-stigmatisation
viii. Respect for diversity, cultural and religious

To put this research in the local legal context, this chapter contains a review of the main laws in South Africa that are applicable to the DNA identification of unidentified human remains. The Bill of Rights of the Constitution of the Republic of South Africa (21) is considered and the legislation specifically addressing the DNA subject in a forensic setting, the Criminal Law (Forensic Procedures) Amendment Act, 2013 (DNA Act) is evaluated (22).

6.2 The Bill of Rights

To introduce context in which the Criminal Law (Forensic Procedures) Amendment Act, 2013 is to be analysed, the human rights foundation of the Constitution is highlighted. Next, a very brief interpretation of the rights that can be related to the issue of DNA identification is offered and the section is concluded with a comment on the consistency of the Bill of Rights and the ethical framework that was outlined in the previous chapter.

The final text of the Constitution of the Republic of South Africa (21), (the Constitution), was introduced into law by then President Nelson Mandela in December 1996. The Constitution commenced on 4 February 1997.
Of the fundamentals the new democratic state was to be founded on, the values of:

> "[h]uman dignity, the achievement of equality and the advancement of human rights and freedoms." (21)

took the prime position in section 1. The clause of supremacy of the Constitution dictates all other law and conduct in the Republic of South Africa must be subject to the constitutional provisions.
The Bill of Rights of the Constitution of the Republic of South Africa (21), (the Bill of Rights), embraces the "values of human dignity, equality and freedom" that comprise a foundation of democracy in South Africa. The Bill of Rights includes the civil and political, economic, social and cultural rights and compels the state to "respect, protect, promote and fulfil" these rights. The human rights in the Bill of Rights which apply to the topic of this research, the DNA identification of human remains, are of civil nature and encompass the "equality", "human dignity", "freedom and security of the person", "privacy" and "freedom of religion, belief and opinion". (21)

6.2.1 Equality

Section 9 of the Bill of Rights protects the equality of all before the law and forbids any unfair discrimination on the grounds of:

> "[r]ace, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth." (21)

The right to equality provides protection for vulnerable groups and communities, promotes equality, guards against discrimination and stigmatization and recognizes diversity amongst people of South Africa.

6.2.2 Human dignity

Section 10 of the Bill of Rights affirms the dignity is inherent to every person and prescribes respect and protection of this right.
The regard for human dignity and upholding of human rights is a driving force behind the basic set of ethical values that were derived from the UNESCO's 2005 Universal Declaration (67) and listed in the introductory section of this chapter.

6.2.3 Freedom and security of the person

The right to "bodily and psychological integrity" is enshrined in section 12 of the Bill of Rights. This section acknowledges the right to "control over ... body", prescribes the informed consent for medical or scientific research and prohibits treating any person in a "degrading way" (21). The right of a person to control over their body ensures the autonomous decision making and confirms the consent to any procedures on their body should be informed.

6.2.4 Privacy

The right to privacy affirmed in section 14 of the Bill of Rights can be interpreted as the right to integrity of personal information which has to be protected against unauthorized access and use. The right to privacy implies the protection of

confidentiality; with the protection of genetic data falling under the ethical subjects of privacy and confidentiality.

6.2.5 Freedom of religion, belief and opinion

Section 15 of the Bill of Rights provides for the freedom of religious and cultural ceremonies under the condition that this right does not contradict the provisions of this section or other provisions of the Constitution. The respect for religious and cultural diversity is enshrined in this section.

A concise examination of certain civil rights enshrined in the Bill of Rights of the Constitution of the Republic of South Africa, 1996 clearly underscores the uniformity of these provisions with the ethical principles that were arrived at in the previous chapter. This is not surprising as the provisions of the Constitution and the Bill of Rights and the set of ethical values to guide DNA identification are firmly rooted in human rights and freedoms.

The supremacy of the Constitution over any legislation in South Africa ensures all legislative statutes in South Africa follow the standard of upholding the basic human rights. The next section deals with the statute which is directly applicable to the issue of use of DNA methodology in the identification, the Criminal Law (Forensic Procedures) Amendment Act, 2013 (22).

6.3 The DNA Act

To conduct an ethical assessment of the DNA Act in context of this research, first, an overview of the DNA Act is given paying close attention to the provisions in relation to missing persons and unidentified human remains. Next, the relevant terms of the DNA Act are discussed through perspective of compliance with fundamental ethical principles and human rights.

Legislation which would address the long lasting expectations of society to reduce the overwhelming crime statistics by utilising forensic DNA analysis was impatiently awaited. The Criminal Law (Forensic Procedures) Amendment Act, 2013 (22) was

introduced into law on 31 January 2015, except for section 2 (23). The act, called the "DNA Act", is designed to build and maintain the DNA identification programme in South Africa, chiefly for the purposes of criminal justice. One of the functions of the National Forensic DNA Database of South Africa initiated by the DNA Act is listed as: "to assist with the identification of missing persons or unidentified human remains." (22)

The DNA Act provides for collection of bodily samples "for the purposes of forensic analysis"; it launches the National Forensic DNA Database of South Africa and provides for the oversight and complaint procedure related to the functioning of the database; it regulates the retention (or destruction) of the DNA samples and created DNA profiles; it stipulates the interim provisions for the DNA profile repository kept currently in the Forensic Science Laboratory. The special consideration is afforded to women and children.

The provisions of the DNA Act related to missing persons and unidentified human remains that need some deliberation from the ethical standpoint can be broken up into the following according to the elements of the DNA identification process:

6.3.1 Collection of DNA samples

Bodily samples which provide a source of DNA comprise buccal samples taken from the mouth of the person and intimate samples, the latter including the blood samples. To protect dignity of the individual whom a sample is to be taken from, the DNA Act prescribes buccal sample collection to be carried out by an authorised police official of the same gender as the donor of the sample and with "strict regard to decency and order". (22) Alternatively, the police official may supervise the taking of the buccal sample by the donor person himself or herself.

For the purpose of obtaining samples from volunteer donors who include the relatives of the missing persons, buccal samples are to be collected. There is an option of collecting blood samples from the person but this procedure has to be performed by a registered nurse or a medical practitioner.

In cases of collecting samples from a living person, the consent of that person is required which must be informed. The notion of "informed consent" is recognised for

DNA sample collection when it is to be loaded onto the Investigative Index. The DNA Act prescribes that informed consent is to be reduced to writing “after a police official has informed him or her” (22) of the buccal sample taking procedure; that providing a buccal sample is voluntary; that the resulting evidence may be used in a court of law; that the sample will be used only for the intended specific purpose; and that the DNA profile will be removed from the database following the finalisation of the case. Neither the DNA Act (22) nor the Forensic DNA Regulations, 2015 (75) to the DNA Act stipulate the requirements for consent to be obtained prior to DNA sample collection from the living relatives who provide reference DNA samples for comparison.

Consent for a buccal sample collection that follows provisions for the informed consent prescribed by the section 15K of the DNA Act (22) concerned with the Investigative Index does not fully satisfy the conditions of informed consent which would be required while dealing with family members of the missing who offer reference DNA samples. In case of blood collection consent obtained by a registered nurse or medical practitioner would not be sufficient, as these health care workers are not necessarily familiar with the intricacies of DNA identification procedures to relay them appropriately. This is not in compliance with best practice and has to be attended to at least at the stage of policymaking. The informed consent would have to address the issue of incidental findings and familial searching. The issue of informed consent for DNA identification is tackled and recommendations on the subject are provided in the last chapter of this work.

6.3.2 The National Forensic DNA Database of South Africa

The National Forensic DNA Database of South Africa comprises several separate directories of DNA profiles. The Missing Persons and Unidentified Human Remains Index holds the DNA profiles derived from bodily samples of missing persons or unidentified human remains and is separate from indices applicable to criminal investigations. DNA profiles derived from forensic analysis of the bodily samples are represented in a numerical form. The DNA profile should not contain any data on health, predisposition or physical aspects of the individual, with exception of sex, in order to prevent any violations of privacy.

The forensic DNA database is established in order to perform comparative searches for the purposes including the “identification of missing persons and unidentified human remains”. (22) “Comparative search” is a process of comparing the DNA profiles obtained from the DNA samples with DNA profiles in the relevant directories, including the “Missing Persons and Unidentified Human Remains Index”.

There should be no inclusion into the database of information about the appearance, except for the sex of the person; no medical data of the person and no information related to the person’s history or behaviour in any of indices. The information obtained from forensic DNA analysis is to be handled with observation of strict confidentiality. The sub-index for children is to be included in each of the indices of the database.

Some of the concerns voiced by human rights activists relate to the custody over the National Forensic DNA Database of South Africa by the South African Police Service (SAPS). Prior to enactment of DNA Act, Naidoo (17) argued that the SAPS is a wrong keeper of a forensic DNA database in the developing country as South Africa because of rife corruption within the ranks and lack of accountability for criminal activities of the members. She insisted the police officers should have no authority to collect human tissue samples for the reasons as above. Naidoo proposed the control over the forensic DNA database to be entrusted to forensic medical practitioners who respect ethical principles of informed consent and confidentiality. Her call remained in vain.

Heathfield (16) has identified a potential privacy issue with the current employing of DNA profiling kits AmpFISTR Profiler Plus™ in the forensic biology laboratory of SAPS. Some of the DNA profile patterns obtained by these profiling kits can indicate chromosomal abnormalities in the DNA sample tested. These DNA profiles containing a sensitive genetic information may be entered into and remain on the forensic database contrary to the provisions of the DNA Act which stipulates no medical or health information in the indices and in forensic DNA profiles. Heathfield proposes the definition of the forensic DNA profile be amended to accommodate capability of some profiling markers to reveal genetic conditions and recommends establishing of a policy for loading the DNA profiles onto the National Forensic DNA Database of South Africa.

6.3.3 Retention and disposal of DNA samples

Bodily samples submitted to the forensic laboratory are to be analysed and recorded onto the database within 30 days unless there are compelling reasons for the delay. Three months after the DNA profile is produced and entered into the relevant index the sample is to be destroyed, limiting the potential for unauthorised handling of the samples and invasion of privacy.

6.3.4 Retention and disposal of forensic DNA profiles

The DNA profile on the Missing Persons and Unidentified Human Remains Index is to be stored until the task of identification of a missing person or unidentified human remains is completed. Following the successful identification, the perused DNA profile is to be removed from the database.

6.3.5 Uses of DNA samples and profiles and access to the database

The DNA Act provides for protection of privacy by laying out the safety measures for the forensic database. The DNA profiles stored on the database, including the Missing Persons and Unidentified Human Remains Index, must be used only in accordance with the intended purpose. Any unauthorised use of DNA sample or profile constitutes a punishable offence threatened with imprisonment of the individual or fine when an institution is concerned.
The information on the forensic database is to be kept safe and secure from damage and loss, and unauthorised access, unlawful processing and dissemination.
No provisions to allow for possibility of any research on the stored data have been set out in the statute.

6.3.6 Familial searching

To guard against privacy and human rights violations by controversial familial searches, the DNA Act allows familiar searches exclusively on the indices without implication of criminality. During the procedure of a familial search, the DNA profile of a missing person or a relative of a missing person is compared against the Missing

Persons and Unidentified Human Remains Index and the Crime Scene Index. The familial searching is to be conducted under the supervision of the National Forensic Oversight and Ethics Board. The results of the familial search can be used to conduct interviews with relatives of the incomplete matching individuals or to “identify unidentified human remains”. (22) The DNA Act prescribes a sensitive approach when dealing with the results. The risk of discrimination and stigmatisation inherently associated with familial searching through the forensic database seems to be reduced by limiting the domain of the search to two indices excluding the indices of criminal connotation.

6.3.7 Ethical oversight

To provide knowledgeable control over the implementation of the DNA Act and to prevent ethical flaws in the procedures in the DNA identification, the National Forensic Oversight and Ethics Board was set up, with the members including experts in the fields of forensic science and DNA, constitutional and human rights law and ethicist.

The Board is to regulate the functioning of the National Forensic DNA Database of South Africa including the determination of conditions of familial searching and related training of the responsible personnel. The Board has powers handle any matters related to implementation of the DNA Act. The Board is to attend to any complaints made in respect of alleged misuse of DNA samples and DNA profiles, and breach of security within the database; the outcome of these complaints is to be relayed to the Minister. The criminal matters are to be referred to respective authority and the disciplinary matters to the National Commissioner. The National Commissioner reports back to the Board and to the National Assembly.

The authority of the Board, built on expertise of the members overseeing the compliance with human rights and ethical issues, contributes to building of public trust in DNA identification and eventual successful and unblemished functioning of the programme.

6.4 Concluding remarks

In this chapter reviews and commentary has been provided on the local laws relevant to DNA identification.

Legislative framework pertinent to the DNA identification of unidentified human remains and missing persons in South Africa entails the provisions of the Constitution of the Republic of South Africa, 1996 and the Criminal Law (Forensic Procedures) Amendment Act, 2013. Being the supreme law of the land the values of human rights enshrined in the Constitution are to be abided by parliamentary and executive authorities and incorporated into statutes.

From the overview of the Criminal Law (Forensic Procedures) Amendment Act, 2013 it is quite clear that great care was taken to absorb human rights and ethical principles into the substance of the Act. Generally, the terms of the DNA Act in regard to the missing persons and unidentified human remains, with exception of informed consent, are in compliance with the set of fundamental ethical principles which were formulated and follow the human rights values set in the Constitution. There are no provisions for research on the data stored on the National Forensic DNA Database of South Africa made in the DNA Act.

The ethical concerns in the local literature have to do with mistrust for the South African Police Service, the custodian of the National Forensic DNA Database of South Africa and potential for exposing very sensitive information on genetic abnormality while using the commercially available DNA profiling kits.

The next chapter summarises the main points of this research and offers several recommendations to ensure the DNA identification program in South Africa in relation to human remains continues to conform to fundamental ethical standards and human rights values.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

7.1 Introduction

Identification of deceased persons carries humanitarian and social value and presents a legal obligation worldwide. DNA profiling plays a very important role in the identification of missing persons and unidentified human remains, particularly so when the remains are damaged due to fragmentation, fire or decomposition. Each step of the identification procedure which employs DNA analysis has its own predicaments; these have to be overcome in order to assure the process successfully achieves its goal. The unique character of a building block of human genetic material, the DNA molecule, which determines the individuality of each person, requires a similarly exceptional approach for the protection of the individual and society when DNA testing is carried out.

The dynamic developments in the field of forensic genetics necessitate discussion on the challenges the DNA methodology poses for the ethical frameworks, related legislation and policies in the functioning of the DNA identification program in day-to-day practice and in the extraordinary conditions of mass fatality situations.

The ethics of DNA utilisation for the purposes of the identification of missing persons and unidentified human remains is a subject of current interest which received attention from bioethicists observing the identification operations following natural and man-made disasters and armed conflicts of the past years.

This research report addresses the need to identify the significant ethical and legislative issues to ensure the DNA identification of unidentified human remains procedures in South Africa are compliant with fundamental ethical norms and human rights that instruct the use of DNA technology. It sets out to determine basic ethical standards that require consideration and to develop a set of ethically and legally justifiable guidelines for the personnel involved in the process.
This brought about a review of concerns voiced on the subject in the international and local literature and subsequently to an assessment of terms of the Criminal Law (Forensic Procedures) Amendment Act, 2013, the South African statute specifically

providing for identification using DNA technology, while focusing on its application to matters of unidentified human remains.
The undertaking of this research project generated several reflections which are presented in the following sections below.

7.2 Overall conclusions

To establish a background for the recommendations culminating from this research, some concluding remarks are offered on the issues which were discussed in the previous chapters of this research report. A brief overview is provided of general considerations which are vital for the organisation of a DNA identification programme that is congruent with ethical and legislative provisions. Then the reference is made to the local context by directing the final deliberations at the provisions of Criminal Law (Forensic Procedures) Amendment Act, 2013.

7.2.1 Guiding principles

The dead possess their inherent dignity as human beings who once lived (9). The surviving relatives have rights in respect of knowing the fate of the beloved. The family members are entitled to receive the remains in order to conduct the last rites with observation of cultural and religious traditions and to commemorate their dead. The state has an obligation to protect these values and rights. The provision of legislation, related guidelines and policies is an obligation of law and policy makers. The direct responsibility for humane treatment of the bereaved relatives and ultimate facilitation of the fulfilment of the duties they have to their dead lies in the personnel who have direct contact with the relatives.
The ethical guidelines and policies which the personnel are endowed with enable them to maintain appropriate ethical conduct and make well-informed ethical decisions which ensure the success of the DNA identification efforts and satisfaction of the bereaved relatives.

The ethical guidelines applicable to the utilisation of DNA profiling in the identification programmes are inspired by human rights and universal ethical values. Such principles are founded on respect for human dignity.

The specific phases of the DNA identification process that need to be considered when formulating detailed guidelines and policies should include the following aspects: informed consent and voluntary participation; autonomy of the bereaved relatives in making decisions relating to viewing of the bodies and receiving of information; privacy and confidentiality of personal and genetic information; incidental findings; familial searching; resource allocation and permissible research.
The guidelines and policies must be in compliance with relevant law of the country and should be so designed as to increase the benefits to the individuals and the communities and minimise any foreseeable harms.

In certain circumstances, as in large scale disasters, where maintaining well-established and accepted principles is practically impossible due to severely constrained resources, new adjustments of the standards have to be made in order to compromise (1)(53).
It has to be borne in mind however; standards which are set too low, carry a risk of misidentification and will unacceptably tip the balance toward harms. Some of the standards, especially concerning the protection of personal and genetic information cannot be compromised in any, even the most difficult, conditions (1).

7.2.2 Regulatory framework in South Africa

Appropriate legislation constitutes a definitive protective mechanism of the standards to be applied when the sensitivity of genetic information is concerned.

Solid grounds of a human rights based approach have been laid in the Constitution of the Republic of South Africa, 1996 (21). The reverence of human rights enshrined in the Constitution offers an ultimate context for formulation of statutes, guidelines and policies.

The Criminal Law (Forensic Procedures) Amendment Act, 2013 (22) is, on the whole, in compliance with fundamental ethical standards and human rights. To fulfil its protective role more adequately attention is needed on several issues that arise from the review of local literature and the analysis of the act's provisions regarding DNA identification of missing persons and unidentified human remains.

The standard of informed consent as determined by the DNA Act does not fully comply with universal ethical principles and guidelines made specifically for DNA identification efforts (1). The DNA Act determines an informed consent to be in writing and given by the consenting person following explanations of: the buccal swab procedure; the donation being on voluntary terms; the possibility that the evidence produced during DNA profiling may be used in court; the use of samples and DNA profiles for intended purposes only and the obligatory removal of DNA profiles from the index compiled on voluntary basis. In the circumstances when buccal reference samples are provided by living family members, apart from general provisions, the wholly informed consent must extend to incidental findings and familial searching as these aspects are specific for DNA profiling.

No consideration for any type of research has been included in the DNA Act. It would be within the scope of the National Forensic Oversight and Ethics Board to set criteria for ethically justifiable research which would be permissible to conduct on the samples collected and related forensic DNA profiles created primarily for identification purposes.

Heathfield (16) raises a concern regarding the possibility for infringement of rights to privacy due to the potential of commercial DNA profiling kits uncovering genetic abnormalities in individuals. To solve the problem, Heathfield proposes the definition of a forensic DNA profile is amended and policy on the entry of DNA profiles into the National Forensic DNA Database of South Africa is formulated. One method to ensure confidentiality of medical information is to enter the potentially revealing allele pattern into the database as “failed designation” (16). This solution would provide for the indices of the National Forensic DNA Database of South Africa to be fully congruent with the terms of the DNA Act prohibiting any medical information to be contained on the database. This aspect requires the consideration of the National Forensic Oversight and Ethics Board.

7.2.3 Practical applications

There is a fear (17), which is perhaps not unfounded, that adherence by South African Police Service members engaged in DNA identification procedures to the ethical and legislative standards cannot be fully guaranteed either due to concerns

with past involvement in human rights violations or reportedly ongoing corruption within the ranks.

The general oversight of the practical execution of provisions of the DNA Act is maintained through the establishment of the National Forensic Oversight and Ethics Board. The Board provides an insight on the important implications of forensic DNA uses and recommendations for the significant operational aspects of the National Forensic DNA Database of South Africa. The Board is furthermore tasked with attending to any potential and reported violations of the terms stipulated in the DNA Act to ensure compliance of all the involved stakeholders. Additional control is provided by annual reporting to the National Assembly and detailed ministerial regulations.

Observation of ethical standards by other personnel involved, such as medical practitioners and forensic pathology officers, may be hindered by a lack of clear professional guidelines or policies in place that specifically address the ethical considerations intrinsic to the utilisation of DNA technology in the identification process of the unidentified human remains. Although medical practitioners are bound by medical ethics and recognise basic ethical principles in their practice, they are not necessarily well acquainted with the specific ethical requirements or considerations of DNA profiling and the tenet of ethical decision-making.

The above issues can be addressed by formulating ethical guidelines and policies which aid in the following of general standards of good practice and solving ethical dilemmas that inadvertently arise due to the complexity of the DNA identification process.

7.3 Recommendations

Based on the findings of this research, there is a glaring need for ethically and legally justifiable norms and well-implemented law and policies to regulate the identification procedures when DNA technology is used for the identification of unidentified human remains.

The guidelines and policy recommendations should address the ethical standards which are applicable to all ethically sensitive aspects of the identification process utilising the DNA technology as meticulously as practically possible.
The recommendations put forward in the following sections draw on fundamental ethical principles and human rights. The suggestions are informed by ethical debates on the subject of DNA use in the identification programmes and existing international standards for situations where DNA profiling is widely employed.
These guiding principles are addressed to the policy-makers and the personnel dealing directly and indirectly with DNA profiling in the identification of missing persons and human remains.
These recommendations seek to advance the DNA identification procedures in our local setting and are to be read together with current legislative provisions in South Africa and recognised universal ethical values.

Appropriate mechanisms should be put in place to ensure the conduct of personnel involved in the DNA identification programme conforms to these ethical guidelines and that there are no infractions on human rights.

7.3.1 DNA profiling as an aid to other identification methods

All reasonable steps should be taken to identify remains of deceased persons. Whenever feasible, the DNA profiling should be utilised as one of the scientific methods of identification. In some cases the DNA profiling ensures the identification of the mortal remains that cannot be done by any other means. The usefulness of DNA identification is largely influenced by the technical and economic determinants of the specific circumstances. The high costs of DNA-led programmes in situations of mass disasters need to be balanced against realistic prospects of successfully concluded identifications.

7.3.2 Resource allocation

The main aim of any identification protocol is to confirm the death of a person. Learning that the certain deceased is somewhere in-between multiple victims is not

optimal. The identification efforts should strive to re-associate the remains as this has great psychological and cultural significance for the families suffering loss.

When economical factors constrain the identification efforts, the most effective and ethically justifiable strategy to compromise should be sought. The morally acceptable choices in the setting of limited resources and increased demand, as it is the case in mass fatality situations, are guided by the principle of “greatest good for the greatest number”. (12)

Cost saving in the identification efforts can be achieved by wider use of the other identification methods and centralised management of the programme. It is further recommended that in this regard, protocols and guidelines be developed as part of contingency plans for various mass fatality situations. These plans would be based at the local level. Resource allocation to various scenarios would be considered with regard to the practicalities and capability of each of the stakeholders. There would further be contingency plans for outsourcing the DNA profiling tasks to other forensic laboratories within the country or abroad as the need arises. Such plans would enhance the integration and cooperation of various departments and laboratories around the country and internationally.

7.3.3 Informed consent and voluntary participation

A collection of reference samples from living relatives for matching purposes should be undertaken only with their explicit consent. The consent is to conform to the exhaustive conditions of informed consent set out by the International Committee of the Red Cross (1) for armed conflicts. These principles can be easily conveyed to any type of setting. The explanation provided to the donors of DNA samples must be provided to them in all cases of sample collection, by medical staff or by police officers collecting buccal samples.

The relative who donates the DNA sample should have sufficient understanding of the following aspects of the DNA-led identification procedures:

a) The purpose of collecting the sample from him or her
b) The benefits of participation in the DNA-led identification programme
c) The important risks associated with participation

d) The rules governing the collection, storage, laboratory procedures involved in DNA profiling and disposal of the samples
e) Strict adherence to protection of personal information and genetic privacy
f) The provisions of the consent form
g) The methods of communication between the organisers and the family members
h) The truly voluntary participation in the programme with option to withdraw at any time without the need for any explanations.

The participant in the DNA identification programme should be furthermore made aware of:

i) The possibility of incidental findings and the non-disclosure policy; if this strategy is the adopted one
j) The meaning and implications of familial searching; if this is allowed. This point is especially valid for South Africa as the DNA Act provides for familial searches to be conducted in relation to missing persons and unidentified human remains, and the living relatives.

When it is advisable to pass personal information to third parties, consent for the disclosure should be obtained from the relevant relative (71).

Special consideration should be given when dealing with vulnerable individuals of limited mental capacity, disabled, elderly and children (71). These persons require patience, caring and kind attitude, sensitivity and empathy. Impatience, threatening and uncaring manner increase their distress.

7.3.4 Notification of the families

The family members should be informed about the recovery of the remains and the results of DNA testing in a timely and transparent manner. The personnel who are in direct contact with the bereaved relatives must exercise the utmost insightful and sensitive demeanour not to cause any more distress to the grieving individuals.

7.3.5 Respect for the autonomy of the families

The family members should be afforded free choice to:

a) View the remains of the deceased relative despite the fact that the identification is based on DNA matching
b) Decide if they wish to be kept informed in a continuous manner regarding the recovery and identification of the body parts in cases of fragmentation
c) Determine how the information is to be shared with the remaining family members, friends and other bereaved.

7.3.6 Protection of privacy and confidentiality

Special character of DNA-led identification programme demands dedicated protection of personal information and genetic data.
All information of personal nature must be fiercely protected in a sufficiently secure environment, digital or paper-based. The family members should be informed that their personal information and that of their dead relatives may be shared if necessary within a team. There should be mutual understanding of principles of confidentiality. For passing of the personal information to other parties consent should be obtained. Dissemination of any information for teaching, statistical or research purposes may only be done after full anonymity of the data is assured (71).

DNA profiling should be carried out only by laboratories with capacity for appropriate management and quality control (1). Access to DNA samples while in storage in police station or forensic pathology facility, in transport to the forensic laboratory and in the laboratory itself must be restricted only to authorised personnel. The transport must be undertaken in secure manner and storage under strict access control. Samples from the living relatives must be disposed as soon as DNA profiles are generated. DNA profiles must be destroyed when they have served their purpose. The missing persons and unidentified human remains index must be kept separate from other indices on the National Forensic DNA Database of South Africa; ideally, the missing persons' database should be established separately from the criminal database (76).

7.3.7 Chain of custody

Preservation of the security of evidence in a form of appropriately sustained chain of custody is a mainstay of any forensic work. This also pertains to DNA evidence gathered and utilised in the identification programmes. The chain of custody should be meticulously maintained at all times. The appropriate labelling and keeping up of documentation that proves security of the specimens at all times safeguards against corruption of the programme.

7.3.8 Secondary uses of DNA samples and DNA profiles

In terms of the DNA Act the DNA samples and the derived forensic DNA profiles may be used only for the intended purpose such as crime solving or identification of unidentified human remains. No statutory provisions are made for any secondary uses.

It is proposed that research which serves to improve methodology of DNA-led identification is allowed on samples originally intended for identification, particularly the ones obtained on voluntary basis. This would require thorough consideration of all circumstances and a specific consent from the participants of the identification programme.

The National Forensic Oversight and Ethics Board has mandate which enables interrogation of the subject, and after careful consideration, approval of this type of research which definitively will positively contribute to building up the local capacity in the field.

7.3.9 Oversight

Implementation of statutory provisions and observation of ethical standards should be monitored by certain mechanisms which closely scrutinise compliance.

Good functioning of the identification programme needs to be watched over at the lower planes in addition to the national level of the National Forensic Oversight and Ethics Board and National Assembly. Oversight of implementation of DNA Act provisions and local departmental policies should be instituted at the level of forensic laboratory, police stations and forensic pathology facilities. There should be a designated personnel member who after appropriate training including a

considerable ethics component would be able to coordinate and control adherence of the remaining personnel to the set principles.

According to terms of DNA Act any member of the public may lodge a relevant complaint with the National Forensic Oversight and Ethics Board. To fairly facilitate this process, the public should be given general information on the available steps and requirements of the complaint procedure at the stage of consent.

Following generally established ethical standards and appropriate implementation of legislative provisions, not only ensures efficient running of the DNA-led identification programme but also protects the programme itself by safeguarding against functioning flaws that bring discontent and mistrust of the public. In order to get the most out of these recommendations which were formulated and presented above, and to ensure good practice in DNA identification efforts of unidentified human remains, the coordination of policies between all stakeholders is required.

REFERENCES

1. International Committee of the Red Cross. November 2009. Missing people, DNA analysis and identification of human remains: a guide to best practice in armed conflicts and other situations of armed violence. Available: https://www.icrc.org/eng/assets/files/other/icrc_002_4010.pdf [Accessed 10 March 2014]

2. Graham, E.A. 2006. Disaster victim identification. *Forensic Sci Med Pathol* 2(3):203-207. doi: 10.1007/s12024-006-0011-0

3. South Africa. Department: Science and Technology. 2009 (updated September 2010). DNA profiling. Available: http://www.saasta.ac.za/images/stories/Debates/Resources/Provincial%202011/Biotech%20prov%202011/DNA%20Profiling%20A3%20folded%20to%20A4%20PRINT%20READY%204mm%20bleed.pdf [Accessed: 10 February 2014]

4. Parker, L.S., London, A.J. & Aronson, J.D. 2013. Incidental findings in the use of DNA to identify human remains: an ethical assessment. *Forensic Sci Int Genet* 7(2):221-229. doi: 10.1016/j.fsigen.2012.10.002

5. Levitt, M. 2007.Forensic databases: benefits and ethical and social costs. *Br Med Bull* 83(1):235-248. doi: 10.1093/bmb/ldm026

6. Haimes, E. 2006. Social and ethical issues in the use of familial searching in forensic investigations: insights from family and kinship studies. *J Law Med Ethics* 34(2):263-276. doi: 10.1111/j.1748-720X.2006.00032.x

7. Knoppers, B.M., Saginur, M. & Cash, H. 2006. Ethical issues in secondary uses of human biological materials from mass disasters. *J Law Med Ethics* 34(2):352-365. doi: 10.1111/j.1748-720X.2006.00040.x

8. Cordner, S. & Coupland, R. 2003. Missing people and mass graves in Iraq. *Lancet* 362(9392):1325-1326. doi: 10.1016/S0140-6736(03)14579-5

9. Bagherzadeh, N. 2014. Death in disaster: actions and attitudes towards dead body management after disasters in Yogyakarta. IFHV Working Paper 4(2):65. Available:

http://www.ruhr-uni-bochum.de/ifhv/documents/workingpapers/wp4_2.pdf [Accessed 10 July 2015]

10. Aronson, J.D. Humanitarian DNA identification in post-apartheid South Africa. In: Genetics and the unsettled past: the collision of DNA, race and history, ed. by K.Wailoo, A. Nelson & C. Lee. 2010. pp. 295-312. Available: http://repository.cmu.edu/cgi/viewcontent.cgi?article=1008&context=history [Last accessed: 25 July 2016]

11. London, A.J., Parker, L.S. & Aronson, J.D. 2013. DNA identification after conflict or disaster. *Science* 341(6151):1178-1179. doi: 10.1126/science.1238085

12. Caenazzo, L., Tozzo, P. & Rodriguez, D. 2013. Ethical issues in DNA identification of human biological material from mass disasters. *Prehosp Disaster Med* 28(4):393-396. doi: 10.1017/S1049023X1300040X

13. Williams, R. & Johnson, P. 2004. “Wonderment and dread”: representations of DNA in ethical disputes about forensic DNA databases. *New Genet Soc* 23(2):205-223. doi: 10.1080/1463677042000237035

14. Morris, A.G. 2013. The DNA bill: forensic science in the service of society. *J Afr J Sci* 109(11-12). doi: 10.1590/sajs.2013/a0043

15. Aronson, J.D. 2011. The strengths and limitations of South Africa’s search for apartheid - era missing persons. *Int J Transit Justice* 5(2):262-281. doi: 10.1093/ijtj/ijr013

16. Heathfield, L.J. 2014. Policy required for entry of DNA profiles onto the National Forensic DNA Database of South Africa. *S Afr J Sci* 110(7-8):94-96. doi: 10.1590/sajs.2014/20130374

17. Naidoo, P. In the wrong hands: a DNA database in South Africa. Available: http://dnapolicyinitiative.org/genewatch-forensic-dna/in-the-wrong-hands-a-dna-database-in-south-africa/ [Last accessed 25 May 2016]

18. De Wet, S., Oosthuizen, H. & Visser, J. 2011.DNA profiling and the law in South Africa. *PER/ PELJ* 14(4):171-207. doi:10.4314/pelj.v14i4.6

19. Meintjes-van der Walt, L. 2008. An overview of the use of DNA evidence in South African criminal courts. *SACJ* 21(1):22-62. Available:

https://www.academia.edu/813729/An_overview_of_the_use_of_DNA_evidence_in_South_African_criminal_courts [Accessed: 10 June 2015]

20. Dias, B.G. 2013. Strengthening the fight against crime: is DNA-database an answer? LLM dissertation, University of Pretoria.
Available: http://upetd.up.ac.za/thesis/available/etd-07242013-121340/unrestricted/dissertation.pdf [Accessed 18 February 2014]

21. South Africa. Constitution of the Republic of South Africa, 1996

22. South Africa. Criminal Law (Forensic Procedures) Amendment Act No. 37 of 2013

23. South Africa. 2014. Commencement of the Criminal Law (Forensic Procedures) Amendment Act, 2013 (Act No.37 of 2013). Government Gazette No.38376:89 30 December

24. South Africa. Births and Deaths Registration Act No. 51 of 1992

25. South Africa. 2007. National Health Act of 2003. Regulations: Rendering of Forensic Pathology Service. Government Gazette No. 30075 20 July (Published under Government Notice R636)

26. South Africa. Department of Health. 2007. National code of guidelines for forensic pathology practice in South Africa

27. South Africa. Inquests Act No. 58 of 1959

28. Evert, L. 2011. Unidentified bodies in forensic pathology practice in South Africa: demographic and medico-legal perspective. MSci in Medical Criminalistics dissertation, University of Pretoria [Available: http://repository.up.ac.za/bitstream/handle/2263/24911/dissertation.pdf?sequence=1] Accessed 11 August 2014

29. Ritter, N. 2007. Missing persons and unidentified remains: the nation's silent mass disasters. *Natl Inst of Justice J* 256: 2-7. Available: http://www.nij.gov/journals/256/missing-persons.html [Accessed 11 August 2014]

30. Zietkiewicz, E., Witt, M., Daca, P., Zebracka-Gala, J., Goniewicz, M., Jarzab, B. & Witt, M. 2012. Current genetic methodologies in the identification of disaster victims and in forensic analysis. *J Appl Genetics* 53:41-60. doi: 10.1007/s13353-011-0068-7

31. Hartman, D., Drummer, O., Eckhoff, C., Scheffer, J.W. & Stringer, P. 2011. The contribution of DNA to the disaster victim identification (DVI) effort. *Forensic Sci Int* 205(1-3):52-58. doi: 10.1016/j.forsciint.2010.09.024

32. Butler, J.M. Missing persons and disaster victim identification efforts. Ch. 9. In: Advanced topics in forensic DNA typing. 2012. Elsevier. pp.271-292. doi: 10.1016/B978-0-12-374513-2.00009-9

33. Passarge, E. Molecular basis of genetics. In: Color atlas of genetics. 2012. Available: http://0-ebooks.thieme.com.innopac.wits.ac.za/pdfreader/color-atlas-genetics41792 [Accessed 10 June 2015]

34. Roewer, L. 2013. DNA fingerprinting in forensics: past, present, future. *Investig Genet* 4(1):22. doi: 10.1186/2041-2223-4-22

35. Decorte, R. 2010. Genetic identification in the 21st century – current status and future developments. *For Sci Int* 201(1-3):160-164. doi: 10.1016/j.forsciint.2010.02.029

36. Davison, S., Benjeddou, M. & D'Amato, M.E. 2008. Molecular genetic identification of skeletal remains of apartheid activists in South Africa. *African J Biotechnol* 7(25):4750-4757. doi: 10.5897/AJB08.035

37. Saukko, P. & Knight, B. The establishment of identity of human remains. Ch. 3. In: Knight's forensic pathology. 3 rd ed. CRC Press. 2004. pp. 98-135. doi: doi:10.1201/b13642-4

38. Jordaan, R.A. & Davel, C.J. Termination of legal subjectivity. Ch. 7. In: Law of persons. 4 th ed. Juta. 2005. pp. 472-513

39. De Waal, M.J. & Schoeman-Malan, M.C. Law of succession. 4 th ed. Juta. 2008. p.11

40. The British Psychological Society. Coping if you have been recently or suddenly bereaved. Available: http://www.bps.org.uk/psychology-public/information-

public/coping-if-you-have-been-recently-or-suddenly-bereaved/coping-if [Accessed: 8 May 2016]

41. Eyre, A. 2006. Literature and best practice review and assessment: identifying people's needs in major emergencies and best practice in humanitarian response. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/61224/ha_literature_review.pdf [Accessed: 11 June 2015]

42. Boss, P. 2002. Ambiguous loss: working with families of the missing. *Fam Proc* 41(1):14-17. doi: 10.1111/j.1545-5300.2002.40102000014.x

43. Disaster Action. Disaster victim identification: relatives' experiences. Available: http://www.disasteraction.org.uk/leaflets/disaster_victim_identification_relatives_experiences/ [Accessed: 9 April 2016]

44. Disaster Action. Available: http://www.disasteraction.org.uk/ [Accessed: 9 April 2016]

45. Sumathipala, A., Siribaddana, S. & Perera, C. 2006. Management of dead bodies as a component of psychosocial interventions after the tsunami: a view from Sri Lanka. *Int Rev Psychiatry* 18(3): 249-257. doi: 10.1080/09540260600656100

46. Pan American Health Organization. Management of dead bodies in disaster situations. Disaster manuals and guidelines on disasters series, No. 5. Available: http://www.who.int/hac/techguidance/management_of_dead_bodies.pdf [Accessed: 11 April 2016]

47. Calacal, G. & De Ungria, M. 2013. Why identify the dead? The Philippine Star. Available: http://www.philstar.com/science-and-technology/2013/06/20/955847/why-identify-dead [Accessed 13 August 2014]

48. Peschel, O. & Eisenmenger, W. Airplane crashes and other mass disasters. In: Encyclopedia of Forensic Sciences. 2 nd ed.Elsevier. 2013. pp. 188-192. doi: 10.1016/B978-0-12-382165-2.00182-3

49. Crettol, M. & La Rosa, A. 2006. The missing and transitional justice: the right to know and the fight against impunity. *International Review of the Red Cross*

88(862):355-362. Available: http://www.icrc.org/eng/assets/files/other/irrc_862_crettol-larosa.pdf [Accessed 11 August 2014]

50. Haimes, E. & Toom, V. 2014. Hidden in full sight: kinship, science and the law in the aftermath of the Srebrenica genocide. *New Genet Soc* 33(3):277-294. doi: 10.1080/14636778.2014.946004

51. Lehrman, S. 2006. Missing no longer. Sci Am 295(3):18-20. Available: http://0-web.b.ebscohost.com.innopac.wits.ac.za/ehost/detail/detail?sid=6f204f82-6dac-4532-9ef4-5fa61ef4c21d@sessionmgr114&vid=0&hid=118&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ==#db=pbh&AN=21847843 [Accessed 12 August 2014]

52. Rosenblatt, A. 2010. International forensic investigations and the human rights of the dead. *Hum Rights Q* 32(4):921-950. doi: 10.1353/hrq.2010.0015

53. Stover, E., Haglund, W.D & Samuels, M. 2003. Exhumations of mass graves in Iraq: considerations for forensic investigations, humanitarian needs and the demands of justice. *JAMA* 290(5):663-666. doi: 10.1001/jama.290.5.663.

54. South Africa. Promotion of National Unity and Reconciliation Act 34 of 1995

55. Krüger G. 2013. The restitution of bones: memory and DNA identity. Keynote address II at 2013 Alltagswohe Fest. Politics of memory, practices of remembrances. April 2013. Available: https://www.academia.edu/4539235/The_Restitution_of_Bones_Memory_and_DNA_Identity [Accessed 7 December 2016]

56. Ballantyne, J. 1997. Mass disaster genetics. *Nat Genet* 15:329-331. doi: 10.1038/ng0497-329

57. Inter - Agency Standing Committee. June 2006. Protecting persons affected by natural disasters. IASC operational guidelines on human rights and natural disasters. Available: http://www.preventionweb.net/files/15342_2006iascnaturaldisasterguidelines.pdf [Last accessed 1 August 2016]

58. Gonzales, A.R., Schofield, R. & Schmitt, G.R.2006. Lessons learned from 9/11: DNA identification in mass fatality incidents. National Institute of Justice working paper. Available: https://www.ncjrs.gov/pdffiles1/nij/214781.pdf [Accessed 5 August 2014]

59. Otto, H. & Hosken, G. 2006. DNA test backlogs delay justice. IOL News South Africa. Available: http://www.iol.co.za/news/south-africa/dna-test-backlogs-delay-justice-282752 [Accessed: 5 December 2016]

60. Keating, B., Bansal, A.T., Walsh, S., Millman, J., Newman, J., Kidd, K. *et al.* 2012. First all-in-one diagnostic tool for DNA intelligence: genome-wide inference of biogeographic ancestry, appearance, relatedness, and sex with the Identitas v1 forensic chip. *Int J Legal Med* 127(3):559-572. doi: 10.1007/s00414-012-0788-1

61. The National Commission for the protection of human subjects of biomedical and behavioural research. April 1979. The Belmont Report. Ethical principles and guidelines for the protection of human subjects of research. Available: http://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/# [Last accessed 1 August 2016]

62. Keane, M.A. 2008. Institutional review board approaches to the incidental findings problem. *J Law Med Ethics* 36(2):352-355. doi: 10.1111/j.1748-720X.2008.00279.x

63. South Africa. Annual report of the National Forensic Oversight and Ethics Board for the period: 1 April 2015-31 March 2013 and progress report for the period: 1 April 2016-16 November 2016. November 2016. Available: http://dnaproject.co.za/blog [Accessed 5 December 2016]

64. DNA Board on its 2015/16 annual report. November 2016. Available: http://dnaproject.co.za/blog [Accessed 5 December 2016]

65. Van Camp, N., Dierickx, K. 2008. The retention of forensic DNA samples: a socio-ethical evaluation of current practices in the EU. *J Med Ethics* 34(8):606-610. doi: 10.1136/jme.2007.022012

66. Lorente, J.A., Entrala, C., Alvarez, J.C., Lorente, M., Arce, B., Heinrich, B. et al. 2002. Social benefits of non-criminal genetic databases: missing persons and human remains identification. *Int J Legal Med* 116(3):187-190. doi: 10.1007/s004140100255

67. United Nations Educational Scientific and Cultural Organization. October 2005. Universal Declaration on Bioethics and Human Rights. Available: http://unesdoc.unesco.org/images/0014/001461/146180E.pdf [Accessed 2 July 2016]

68. International Federation of Red Cross and Red Cross Societies. Fundamental principles – Humanity. Available: http://www.ifrc.org/en/who-we-are/vision-and-mission/the-seven-fundamental-principles/humanity/ [Accessed 11 August 2014]

69. Rosenblatt, A. 2008. Last rights: international forensic investigations and the claims of the dead. Conference paper. Available: http://iis-db.stanford.edu/evnts/5198/RosenblattLastRights.pdf [Accessed 13 August 2014]

70. International Committee of the Red Cross. February 2009. Guiding principles/ model law on the missing. Principles for legislating the situation of persons missing as a result of armed conflict or internal violence: measures to prevent persons from going missing and to protect the rights and interests of the missing and their families. Available: https://www.icrc.org/en/download/file/1066/model-law-missing-icrc-eng-.pdf [Accessed 13 August 2014]

71. Disaster Action. 2006. Working with disaster survivors and the bereaved: code of practice on privacy, anonymity & confidentiality. Available: http://www.disasteraction.org.uk/leaflets/working_with_disaster_survivors_and_the_bereaved_code_of_practice_on_privacy_anonymity_and_confidentiality/ [Accessed 10 May 2016]

72. Disaster Action. 2008. Disaster victim identification: issues for families and implications for police family liaison officers and coroner's officers. Available: http://www.disasteraction.org.uk/leaflets/Guidance_for_Responders_Disaster_Victim_Identification_Issues_for_Families_and_Implications_for_Police_Family_Liaison_Officers_and_Coroners_Officers.pdf [Accessed 10 May 2016]

73. Dix, P. 1998. Access to the dead: the role of relatives in the aftermath of disaster. *Lancet* 352(9133):1061-1062. Available: http://0-web.b.ebscohost.com.innopac.wits.ac.za/ehost/pdfviewer/pdfviewer?sid=f5b20520-eaba-4444-8857-1f45e2c7adb1@sessionmgr198&vid=1&hid=116 [Accessed 25 June 2015]

74. Lawler, A. 2001. Terrorism. Massive DNA identification effort gets under way. *Science* 294(5541):278-279. doi: 10.1126/science.294.5541.278

75. South Africa. 2015. Criminal Law (Forensic Procedures) Amendment Act of 2013. Regulations: Forensic DNA. Government Gazette No. 38561 13 March (Published under Government Notice R207)

76. Forensic Genetics Policy Initiative. 2013. Comments on Criminal Law (Forensic Procedures) Amendment Bill South Africa. Available: http://www.councilforresponsiblegenetics.org/pageDocuments/EK6FT2MQBR.pdf [Accessed 14 July 2016]

APPENDIX A: Ethics clearance certificate

Human Research Ethics Committee (Medical)

Research Office Secretariat: Senate House Room SH 10005, 10th floor. Tel +27 (0)11-717-1252
Medical School Secretariat: Medical School Room 10M07, 10th Floor. Tel +27 (0)11-717-2700
Private Bag 3, Wits 2050, www.wits.ac.za. Fax +27 (0)11-717-1265

Ref: W-AW-140331-1 31/03/2014

TO WHOM IT MAY CONCERN:

Waiver: This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical).

Investigator: Bozena Krysztofiak (Student number 511713)

Project title: DNA PROFILING OF UNIDENTIFIED HUMAN REMAINS IN THE SOUTH AFRICAN CONTEXT: AN ETHICO-LEGAL ANALYSIS

Reason: The aim of this research is to determine what legal regulatory provisions and professional ethical guidelines are needed in South Africa to ensure that the moral and ethical considerations relating to DNA identification of unidentified human remains are addressed? As such this research will not involve any human or animal participants and no new data will be collected or analysed. The research will be conducted using the internet and library resources.



Professor Angela Woodiwiss

Co-Chair: Human Research Ethics Committee (Medical)

Copy: Anisa Keshav and Zanele Ndlovu, Research Office, Senate House, Wits